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TITLE OF THE ARTICLE

Management of erectile dysfunction after prostate cancer treatment – surveys of the perceptions and experiences of patients and healthcare professionals in the UK

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ABSTRACT

Objectives: Erectile dysfunction (ED) is known to be a common consequence of treatment for prostate cancer but is often under-reported and under-treated. This study aimed to explore how ED in prostate cancer patients is managed in real-life clinical practice, from the perspective of patients and healthcare professionals (HCPs).

Setting: 546 men with ED after prostate cancer treatment, 167 primary (GPs and practice nurses) and 94 secondary care HCPs (urologists and urology Clinical Nurse Specialists).

Design: A UK-wide online survey of men with ED after treatment for prostate cancer which covered assessment and discussion of erectile function, provision of supportive care and satisfaction with management. Parallel surveys of primary and secondary HCPs were also conducted.

Results: Survey findings revealed inadequate management of ED in primary care, particularly under-prescribing of effective management options. A fifth of men (21%) were not offered any ED management and a similar proportion (23%) were not satisfied with the way that HCPs addressed their ED concerns. There was poor communication between HCPs and men, including failure to initiate discussions about ED and/or involve partners, with 12% of men not told that ED was a risk factor of prostate cancer treatment. These issues seemed to reflect poor access to effective ED management or services and lack of primary HCP confidence in managing ED, as well as confusion over roles and responsibilities among both HCPs and men.

Conclusions: This study confirms the need for better support for men from HCPs and more tailored and timely access to effective ED management after treatment for prostate cancer. A clearly defined pathway is required for the discussion and management of ED, starting from the planning stage of prostate cancer treatment. Improved adherence to ED management guidelines and better education and training for primary care HCPs are areas of priority.

ARTICLE SUMMARY: Strengths and limitations of this study

- This is the first UK study to survey the perceptions and experiences of men with erectile dysfunction after prostate cancer treatment and therefore adds considerable knowledge to the field.

- Also surveying primary and secondary HCPs on the same topics revealed additional unique challenges in treating management coordination for these men.

- Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received.

- Compliance with ED treatment was not explored.

- The surveys were conducted before the availability of generic / over-the counter sildenafil and generic tadalafil.

INTRODUCTION

In 2018, 1.28 million men were diagnosed with prostate cancer worldwide, which represented 13% of all cancers diagnosed in men.[1,2] In the UK, prostate cancer is the most common cancer in men, with over 56,000 new cases diagnosed in 2018.[3] Treatments for prostate cancer include radical prostatectomy (RP), external beam radiotherapy (EBRT), brachytherapy, High Intensity Focused Ultrasound (HIFU) and androgen deprivation therapy (ADT).[4,5]

While effective in prolonging survival,[6] these treatments commonly induce erectile dysfunction (ED).[7–9] The UK-wide Life After Prostate Cancer Diagnosis (LAPCD) study examining patient-reported outcomes of over 30,000 prostate cancer survivors at 18-42 months after diagnosis recently reported that 81% of patients described their overall sexual function as poor or very poor.[10] By comparison, the prevalence of poor sexual function in the general population of men aged 60 and over is 33%.[11]

Typically, ED, accompanied by gradual structural changes in the penis, develops over a few months and up to 2-3 years after treatment and may be permanent. ADT may also cause loss of sexual interest, as well as more general symptoms such as fatigue, low mood, weight gain and decreased muscle mass. ED has been linked to loss of self-esteem, and depression,[12] and can significantly impair quality of life for both men and their partners.[7,8,10,13]

A wide range of treatments are available for the management of ED, including oral phosphodiesterase type 5 inhibitors (PDE5i), intracavernosal injections (ICI), intraurethral suppositories or ointment (alprostadil), vacuum erection devices (VED) and penile implants.[4,5,14] Nevertheless, ED remains an under-reported and often under-treated condition [15–18]. The LAPCD study reported that only 44% of men were offered intervention(s) to help with sexual function such as medications, devices or specialist services.[10] A recent review from a high-volume centre suggested that despite the advancements in surgical and post-operative care, erectile function outcomes after radical prostatectomy have not improved over the last decade and more efforts are needed to improve patient's care after radical prostatectomy.[19]

To address healthcare professionals' (HCP) concerns that no UK guidelines were available for the management of ED in prostate cancer patients, specific consensus guidelines for treating ED after prostatectomy [7] or radiotherapy/ADT [8] have been developed. These guidelines emphasise the importance of proactive early sexual rehabilitation post-prostatectomy, including patient education and pharmacological intervention, to minimise treatment-induced penile changes and to actively manage the impact of loss of sexual desire and delayed ED post-radiotherapy/ADT on men and their partners.

The aim of this study was to explore how ED after prostate cancer treatment is experienced, assessed and managed in a publicly-funded health care system, from the perspectives of both patients and HCPs. We conducted a UK-wide survey of men with ED after prostate cancer treatment and parallel surveys of primary and secondary HCPs, including GPs, practice nurses, urologists and urology Clinical Nurse Specialists (CNS).

METHODS

Study design

An online survey of men experiencing ED after prostate cancer treatment was conducted between August 2014 and March 2015. Survey questions explored the assessment and discussion of erectile function (EF) with HCPs and satisfaction with ED management. To recruit participants, a hyperlink to the open online survey was widely disseminated through Prostate Cancer UK's communication channels including electronic newsletters and social media. Paper versions of the survey were also provided upon request and these results were manually entered into the dataset. Responses from 561 men with ED after prostate cancer were received (a self-selecting convenience sample). Responses from 15 men who had not received treatment in the UK were excluded, leaving a total of 546 respondents for analysis. The number of responses per question ranged from 408 to 546 (75-100% response rate) due to respondents selecting they did not know the answer or that the question did not apply to them.

Online surveys of GPs, practice nurses, urologists, and urology CNSs were conducted between October 2014 and January 2015. Survey questions explored confidence regarding knowledge of prostate cancer and ED (primary HCPs only), discussions about potential side effects of prostate cancer treatment, how EF is assessed, the involvement of partners, ED management options and roles and responsibilities. Participants were invited via Doctors.net.uk and Nursing in Practice access panels, weighted on gender, age and location to be representative of the respective HCP populations. A total of 282 HCP questionnaires were received; 21 responses were excluded from the analysis due to duplicate entries, leaving a total of 261 HCPs in the analysis (115 GPs, 52 practice nurses (four of whom were nurse practitioners/advanced nurse practitioners), 50 urologists and 44 urology CNSs).

Questions for both surveys were co-produced by men living with and after prostate cancer and HCPs. Before beginning each survey, participants were informed of the approximate length of time to complete the survey, the purpose of the study, that their responses would be confidential and not used for any other purposes beyond this research study and contact details of the study team. Where appropriate, questions and response options were randomized to reduce bias. Only completed questionnaires were included in the final dataset.

Statistical analysis

Data were analysed based on the number and percentage of respondents to each question. For the survey of men with ED after prostate cancer treatment, responses were grouped and analysed by type of prostate cancer treatment received.

Patient and public involvement statement

The Prostate Cancer UK 'Policy & Campaigns Forum', consisting of men living with and after prostate cancer, initially raised the issues around ED after prostate cancer treatment as a suggested area of work for Prostate Cancer UK to focus on. The Forum members were subsequently involved in the planning of the study, including development of the research questions and survey design.

RESULTS

Survey of men with ED after prostate cancer treatment

Respondent characteristics

The mean respondent age was 65 years, with half (n=280/546; 51%) of the study sample aged between 60-69 years (**Supplementary File 1**). Over three-quarters (n=422/544; 78%) were married or in a civil partnership and most (n=513/543; 94%) indicated that they were 'heterosexual/straight', while 3% (n=17) described themselves as 'gay' and 2% (n=13) as 'bisexual'. The majority (n=400/546; 73%) of respondents received their prostate cancer treatment in England, with the remainder (27%) receiving treatment throughout the rest of the UK (**Supplementary File 1**).

Approximately half (n=286/546; 52%) of respondents received their initial treatment in 2010 or later, while the remainder were treated before 2010. The majority (n=333/546; 61%) received only one treatment, while 30% (n=160) received two and 5% (n=26) three. The most common treatment was radical prostatectomy (n=310/546; 57%), either alone (n=258; 47%) or in combination with other treatment(s) (n=52; 10%). One-quarter of patients (n=137/546; 25%) received EBRT and one-third (n=182; 33%) received androgen deprivation therapy (ADT) (**Supplementary File 2**).

Men's experiences prior to prostate cancer treatment

Almost three-quarters of respondents (n=401/546; 73%) indicated that they had 'always'/'almost always' been able to get and keep an erection before their prostate cancer treatment with only 2% (n=10) stating they were not sexually active before treatment (**Table 1a**).

Over one-third (n=191/525; 36%) reported that their consultant was the first HCP to question them about their EF before treatment, while another third (n=182; 35%) reported that no one had asked about this (**Table 1b**). Less than 10% (n=48/546; 9%) of respondents had completed a pre-treatment standard questionnaire, such as the Sexual Health Inventory for Men (SHIM) [20] or International Index of Erectile Function (IIEF) [21]. Men who were to undergo prostatectomy were more likely to be asked to complete a questionnaire, compared to men who were to receive radiotherapy with ADT (14% versus 6%, respectively).

Most respondents (n=447/546; 82%) were told by their doctor or nurse that ED might be a side effect of their treatment, however 12% (n=68) were not told this information. This information was more likely to be given to men before a prostatectomy, compared to radiotherapy and ADT (91% versus 74%, respectively) (**Table 1c**). For respondents with a partner (n=473), 70% (n=332) said their partners were involved in these discussions with their HCPs. The knowledge of possibly experiencing erection difficulties influenced the choice of prostate cancer treatment for 13% (n=74/546) of men.

Table 1. Men's experiences prior to prostate cancer treatment

a. How often were you able to get and keep an erection before prostate cancer treatment? (n=546)

	Total	Surgery	RT+ADT	Other
Almost always/always	**401 (73%)**	205 (79%)	75 (64%)	121 (71%)
Most times (>50%)	**64 (12%)**	21 (8%)	18 (15%)	25 (15%)
Sometimes (~50%)	**30 (5%)**	16 (6%)	6 (5%)	8 (5%)
A few times (<50%)	**24 (4%)**	10 (4%)	7 (6%)	7 (4%)
Almost never/never	**14 (3%)**	4 (2%)	7 (6%)	3 (2%)
No sexual activity	**10 (2%)**	1 (0%)	3 (3%)	6 (4%)
Unsure	**3 (1%)**	1 (0%)	2 (2%)	0 (0%)
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**

b. Who asked the first questions about your erections before treatment? (n=525)

	Total	Surgery	RT+ADT	Other
Your consultant	**191 (36%)**	123 (49%)	22 (20%)	46 (28%)
Your GP	**14 (3%)**	6 (2%)	2 (2%)	6 (4%)
Your Nurse	**35 (7%)**	17 (7%)	9 (8%)	9 (5%)
Your Partner	**4 (1%)**	1 (0%)	0 (0%)	3 (2%)
You	**99 (19%)**	47 (19%)	19 (17%)	33 (20%)
No one	**182 (35%)**	55 (22%)	60 (54%)	67 (41%)
Total (% of total)	**525 (100%)**	**249 (47%)**	**112 (21%)**	**164 (31%)**

c. Did your doctor or nurse tell you that erectile dysfunction might be a side effect of treatment? (n=546)

	Total	Surgery	RT+ADT	Other
Yes	**447 (82%)**	235 (91%)	87 (74%)	125 (74%)
No	**68 (12%)**	11 (4%)	21 (18%)	36 (21%)
Unsure	**28 (5%)**	10 (4%)	9 (8%)	9 (5%)
ED not a side effect of the treatment I had	**3 (1%)**	2 (1%)	1 (1%)	0 (0%)
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**

Percentages in brackets are a percentage of each column, unless otherwise stated.

"Total" All men who took part in the survey and reported ED following treatment

"Surgery" Men whose only radical treatment was radical prostatectomy

"RT+ADT" Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT

"Other" All men who received a treatment other than "surgery" or "RT + ADT"

Men's experiences after prostate cancer treatment

Following prostate cancer treatment, half (n=229/437; 52%) of men were asked about their EF by their HCP within 3 months (**Table 2A**), most commonly by their consultant, and this rose to 69% (n=156) in the group that had prostatectomy. However, 29% (n=127) of all respondents said they had not been asked by any HCP about EF following prostate cancer treatment (**Table 2A**). Almost a quarter (n=123/489; 23%) of men were not satisfied with the way that HCPs addressed their EF concerns.

Treatment for ED

Two-fifths of men (n=199/503; 40%) said they were offered ED treatment within 3 months of their prostate cancer treatment, with a further 19% (n=94) being offered treatment within 4-6 months. A fifth of men (n=110; 22%), said they were not offered any treatment (**Table 2B**). Treatment was most commonly offered by a consultant (n=230/516; 45%) and usually in a urology department (n=181/503; 36%), GP surgery (n=120; 24%) or ED clinic (n=89; 18%).

ED management options men were offered for ED are shown in **Supplementary File 3** (n=521): most commonly they were offered 3 options (n=122/521; 29%). The most common treatments offered were sildenafil 25, 50 or 100mg (16%, 20%, 17%), VED (33%), tadalafil 5, 10 or 20mg (21%, 14%, 29%) and pelvic floor exercises (20%), mostly on NHS prescription. The most common treatments prescribed privately were also PDE5i and VED.

When asked whether they had any difficulty or delays in getting access to ED treatment, one-quarter (n=103/431; 25%) indicated experiencing such problems. These included issues with supply and availability such as 'restricted availability due to limited prescriptions', 'pharmacies lacking stock', 'cost' and 'HCPs not being helpful/willing to prescribe/lacking knowledge'.

Table 2. Men's experiences after prostate cancer treatment

a. How soon after prostate cancer treatment, if at all, did the consultant, GP or nurse ask whether your ability to get or keep an erection had been affected? (n=437)

	Total	Surgery	RT+ADT	Other
≤3 months	**229 (52%)**	156 (69%)	29 (33%)	44 (35%)
4-6 months	**59 (14%)**	34 (15%)	7 (8%)	18 (14%)
7-12 months	**16 (4%)**	5 (2%)	4 (5%)	7 (6%)
>12 months	**6 (1%)**	1 (<1%)	1 (1%)	4 (3%)
Not at all	**127 (29%)**	29 (13%)	46 (53%)	52 (42%)
Total (% of total)	**437 (100%)**	**225 (51%)**	**87 (20%)**	**125 (29%)**

b. How long after prostate cancer treatment, if at all, were you offered treatment to help you get or keep an erection? (n=503)

	Total	Surgery	RT+ADT	Other
<3 months	**199 (40%)**	128 (54%)	24 (23%)	47 (29%)
4-6 months	**94 (19%)**	53 (22%)	12 (11%)	29 (18%)
7-12 months	**38 (8%)**	20 (8%)	6 (6%)	12 (8%)
>12 months	**28 (6%)**	8 (3%)	12 (11%)	8 (5%)
Unsure	**34 (7%)**	10 (4%)	9 (8%)	15 (9%)
Not at all	**110 (22%)**	18 (8%)	43 (41%)	49 (30%)
Total (% of total)	**503 (100%)**	**237 (47%)**	**106 (21%)**	**160 (32%)**

Percentages in brackets are a percentage of each column, unless otherwise stated.

"Total"	All men who took part in the survey and reported ED following treatment
"Surgery"	Men whose only radical treatment was radical prostatectomy
"RT+ADT"	Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT
"Other"	All men who received a treatment other than “surgery” or “RT + ADT”

Monitoring of ED treatment

Over three quarters of respondents (n=374/484; 77%) said they were not asked any questions about their response to ED management, or asked to complete a questionnaire, such as the SHIM or IIEF, during ED treatment. When asked whether their prescribed ED treatment met their needs, only 32% (n=128/402) said ‘yes’, while 51% (n=204) said ‘no’ and 17% (n=70) were ‘unsure’. Approximately half of the respondents (n=298/546; 55%) reported having access to a CNS, with the remainder saying they did not have access, or were uncertain.

Survey of primary and secondary healthcare professionals

Respondent characteristics

The majority of HCPs surveyed were located in England (n=229; 85%). Half (n=59/115; 51%) of the GPs surveyed were seeing less than 5 prostate cancer patients per month. Practice nurses saw patients with ED relatively frequently, usually on a weekly (n=25/52; 48%) or monthly (n=11; 21%) basis. One-quarter (n=10/44; 23%) of the CNSs indicated that they specialised in ED management, while the remainder specialised in urology.

Knowledge and confidence in ED management within primary care

GPs and practice nurses were asked how confident they were that their knowledge of prostate cancer, ED and treatment options for ED was sufficiently comprehensive and up-to-date to support men with prostate cancer. Most GPs indicated their knowledge as ‘satisfactory’/’confident’/’very confident’ for prostate cancer (n=98/115; 85%), for ED (n=104; 90%) and for treatment options for ED (n=108; 94%), compared to 48% (n=25/52), 34% (n=18) and 32% (n=17) of practice nurses, respectively, with the remainder stating they were ‘apprehensive’ or ‘extremely unconfident’ (**Figure 1**). When asked what would help to improve their confidence, the most common responses were ‘training/education’, and ‘further information/literature/online resources’.

Discussions about ED

Only 26% of GPs (n=30/115) and 32% of practice nurses (n=16/51) said they ‘usually’/‘always’ initiated a discussion about ED with men after prostate cancer treatment, with 28% (n=33) and 38% (n=19), respectively, saying they ‘rarely’/’never’ did so. The most common reasons GPs gave for not initiating a discussion about ED were that it ‘wasn’t a priority topic’ or that ‘the patient initiated the discussion’. However, 32% of GPs (n=37/115) said that men ‘rarely’/’never’ initiated a discussion about ED with them, while 25% of practice nurses (n=13/51) said the same.

When secondary care HCPs were asked who was the most likely to initiate a discussion about ED, the majority of urologists (n=33/50; 61%) identified themselves, while for non-ED specialist CNSs (n=34) the most common first choice was the patient (n=12; 35%), followed closely by the urologist or urology/uro-oncology CNS (both n=11; 32%). A fifth of urologists (n=10/50; 20%) said that the duration of ADT would affect their decision whether to discuss ED with the patient, with the conversation more likely to take place for men on long-term ADT.

Involvement of partners in discussions about ED appeared to be more common in secondary care. 40% of urologists (n=20/50) versus only 13% of GPs (n=15/115) said they ‘usually’/’always’ involved men's partners in such discussions, while 24% of urologists (n=12/50) versus 60% of GPs (n=70/115) said they ‘rarely’/’never’ did so. Among the nurses surveyed, 65% of CNSs (n=28/43) said they involved partners, compared to only 12% of practice nurses (n=6/51).

Assessment of erectile function in secondary care

The majority of CNSs (34/44; 77%) and urologists (40/50; 80%) said they 'usually'/'always' performed a verbal baseline assessment of EF before treatment, with only 8% of urologists (n=4) saying they 'never'/'rarely' did this. Standardised questionnaires were used less frequently than verbal assessments by both urologists and CNSs. 30% (n=15/50) of urologists indicated that there were some patient groups they chose not to assess for baseline EF, for example if they were very elderly, had advanced disease or did not wish to be assessed. Other factors such as lifestyle, medication, comorbidities and relationships were also often included in the EF assessment.

Roles and responsibilities

Primary and secondary care HCPs were asked which HCPs or services they perceived as being involved in initiating, monitoring and following up on treatment for ED. The pattern of responses differed considerably between different HCP types, as shown in **Figure 2**. GPs and urologists had the most prominent role according to GPs and practice nurses, whereas urologists and CNSs identified themselves and dedicated ED services as playing the major roles. For CNSs, they identified themselves as having a greater focus on monitoring and follow-up than on management initiation.

Management of ED

In primary care, 39% of GPs (n=44/115) said that they 'usually'/'always' prescribed pharmacological management for ED among men affected by prostate cancer, while 51% (n=59) said 'sometimes', and 11% (n=12) 'rarely'/'never' did. Only 23% of practice nurses (n=12/52) said that they offered ED management.

A large majority of GPs (n=104/111; 94%) and urologists (42/50; 84%) used oral therapy (PDE5i) as their first line treatment for ED in prostate cancer patients. The PDE5i most commonly prescribed by GPs was sildenafil (93%), whereas urologists most commonly prescribed tadalafil (96%). Most GPs prescribed a dose of 4 tablets per month: only 38% of GPs, compared to 69% of urologists, prescribed daily low dose (5mg) tadalafil (the only daily PDE5i licensed for daily use).

GPs were much less likely than urologists to use second- or third-line treatments, including VED (15% vs 86%), intracorporeal injections (35% vs 86%), intraurethral PGE-1/alprostadil (17% vs 58%), penile implants (9% vs 28%), combination therapy (1% vs 50%), psychosexual therapy (12% vs 24%) and pelvic floor exercises (12% *vs* 20%) (**Figure 3**). A common reason for this would be that GPs would refer the patient to secondary or specialist care for these treatments. However, 41% of GPs (n=47/115) said they 'rarely'/ 'never' refer men with ED after prostate cancer treatment to secondary or specialist care.

Access to treatments

Treatments reported to be inaccessible to some GPs included penile implants (n=74/115; 64%), intracavernosal injections (n=51; 44%) and VEDs (n=48; 42%). Common reasons given were that these treatments were 'restricted to secondary care', 'not prescribed on the NHS' or 'a lack of training or expertise in their use'. Treatment access was less of an issue among secondary care HCPs: 56% of urologists (n=28) said that all ED treatments, including psychosexual therapy, were available to their patients.

DISCUSSION

Our survey of men explored the experiences of ED management after being treated for prostate cancer. In parallel surveys, we examined the knowledge and experience of primary and secondary HCPs in assessing such patients and their management strategies. Our findings indicated that, despite being at high risk from treatment-induced ED, many men were not treated according to recognised/available ED treatment guidelines available at the time of this study [14,22] and many were dissatisfied with their ED management. There was also an apparent mismatch between patient and HCP views on how post-treatment ED is managed in practice. It seems likely that, to some extent, HCPs' responses may have reflected their 'ideal' management rather than what actually took place in practice.

In particular, there seemed to be inadequate management of ED in primary care, including failure to implement early and structured strategies, combination ED management strategies and, in some instances, any ED treatment at all. These issues seemed to reflect restricted access to treatments and services and lack of confidence in managing ED. This suggests a need for better targeted training and education, particularly for practice nurses. Many GPs see relatively few prostate cancer patients, whereas practice nurses encounter men with ED more frequently, presumably when administering ADT injections or providing care for concomitant conditions, such as diabetes. In the UK there has been minimal under/postgraduate education in sexual medicine and human sexuality.[23,24] We also found a lack of assessment of EF before and after prostate cancer treatment, with low usage of formal/validated measurement instruments (e.g. IIEF, SHIM etc.) and no routine structured evaluation of ED management efficacy.

Communication between HCPs and patients was limited, with failure to initiate discussion of ED and/or involve partners in discussions. It was particularly worrying that 12% of men said they were not told that ED was a risk of prostate cancer treatment. Communication barriers between patients and HCPs are known to be a key factor in the under-reporting, and consequent under-treatment, of ED.[15,16] Understandably, HCPs may hesitate to enquire into personal aspects of men's lives, while men themselves may be too embarrassed to raise the issue,[25,26] believe that ED is an inevitable result of ageing and/or not know which HCP to ask for help.[16] Factors such as advanced patient age may deter GPs from enquiring about sexual activity.[27,28] Although the men in our survey were not young (average age 65 years, with 25% aged ≥70 years), it was clear from their survey responses that sexual activity was still important to them. Other reports suggest that many men wish to continue sexual activity into their 8th and 9th decades.[29,30] Data from the diabetes setting has found patient embarrassment to be the most common reason for under-reporting of ED.[25] In male patients aged >30 years attending their physician, a brief patient questionnaire on EF was found to be an excellent aid for patients and physicians to prompt discussion about ED.[15] Patient reactions to the questionnaire included relief that the issue had been broached and the knowledge that help was available for ED.

As disease surveillance after treatment for prostate cancer generally occurs from 6 weeks post-treatment at 3-monthly intervals for at least 12 months in the UK,[4] it was disappointing that there were delays in initiating ED management within secondary care and poor communication with primary care. The necessary focus on disease surveillance in oncology clinics may result in low prioritisation of sexual difficulties. An observational study found that patients with prostate cancer were more likely to initiate a discussion about sexual function in the urology clinic than in the clinical oncology clinic (22% vs 4%), but nevertheless sexual concerns were not discussed at all in almost 50% of visits.[31]

Importantly, we found considerable differences between HCP opinions regarding lead roles in the initiation, monitoring and follow-up of ED management: such confusion could easily lead to inadequate management and contradictory advice, as was evident from the men's survey results. These findings may reflect financial considerations, and, in the case of nurses, whether or not they have a prescribing role. The increased role of primary care in the follow-up of prostate cancer patients [32] requires unified management guidelines and support from Clinical Commissioning Groups regarding GP prescribing of relevant treatments with local guidelines and shared care protocols. While urologists and specialist ED clinics were most commonly identified as being responsible for prescribing ED treatment, this management route inevitably leads to delays, due to the need for specialist referral and limited access to specialist ED clinics.

Specific consensus guidelines for treating ED after prostate surgery [7] and radiotherapy/ADT [8] have been developed. These guidelines emphasise the importance of proactive early ED management including patient education and pharmacological intervention, to minimise treatment-induced penile changes and the impact of loss of sexual desire and delayed ED on men and their partners.[7,8,33–35] They recommend daily and/or on-demand PDE5is as first-line treatment for patients who have undergone nerve-sparing prostatectomy.[7] PDE5is should be offered early after surgery, within the first month.[35,36] VEDs, alone or in combination with other modalities, may be used if other treatments have proved ineffective.

The finding in this study that many GPs did not prescribe treatments for ED is a matter for concern. Surprisingly, 44% of urologists did not have access to all ED treatments, despite NICE guidance.[4] NHS prescribing of PDE5 inhibitors is

often limited to once-weekly use, which may not adequately support men's needs or specialist sexual rehabilitation programme aims.[37] 'Stinting' on effective treatments such as PDE5i can be a false economy, potentially resulting in treatment failure and the need for expensive secondary referrals.[17,18] It is hoped that the recent availability of reduced cost generic sildenafil and tadalafil, and the lifting of restrictions on its daily use, will allow more men with ED to receive early treatment.

Lack of access to specialist ED services is known to be a challenge for effective ED management, with support from nurses being identified as a significant factor impacting patient outcomes. Sexual counselling is known to contribute to better efficacy, patient acceptance of, and compliance with, other prescribed treatments for ED,[7] but was rarely offered in our survey. The National Prostate Cancer Audit (NPCA) 2014 annual report included results of an organisational audit of prostate cancer services in England and Wales. The audit showed 'sexual function services' to be available in 90% of NHS trusts in England and hospitals in Wales.[38] However, at the time, these data were inconsistent with findings from Freedom of Information requests submitted by Prostate Cancer UK in 2015 to 235 NHS health authorities across the UK to determine the availability of services (ED clinics, psychosexual clinics, and counselling/sexual therapy) and treatments (daily low-dose tadalafil, VEDs and penile implant surgery) for men with ED after prostate cancer treatment. These results indicated poor availability of ED clinics, with only 51% of areas stating they offered this service, with wide geographical variation.[39] The NPCA repeated their organisational audit in 2016/17 and reported that 'sexual function services' were available in 100% of NHS trusts in England and Health Boards in Wales, either provided on site or by the specialist MDT site.[40] Despite the published availability of support services, this does not necessarily translate through to men being offered intervention(s), accepting these interventions(s) or that these intervention(s) are helpful. In a bid to tackle the problem, novel support approaches have been developed such as the Movember Foundation's TrueNTH initiative online self-management programme which provides personalised self-management strategies to help improve sexual wellbeing after prostate cancer.[41]

Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received. Men and partners, physician and nurse's surveys were conducted separately and some response options differed between surveys, limiting direct comparisons. While HCPs generally answered all questions, many of the men's' survey questions were not answered and there were many 'unsure'/'don't know' or 'not applicable' responses. Men received a wide range of prostate cancer treatments: approximately half had undergone surgery (57%), but we were unable to determine how many had undergone nerve-sparing prostatectomy, since this question was not asked. Compliance with ED treatment was not explored. We did not conduct a separate analysis of data from gay and bisexual men, due to the small sample size, although recent data suggest that this group may have additional support needs than do heterosexual men.[42] For the survey of men with prostate cancer, a "convenience sample" was collected, which may limit generalisability of our results. As already noted, the surveys were conducted before the availability of generic and over-the-counter sildenafil and generic tadalafil.

CONCLUSIONS

In conclusion, our survey of men experiencing ED after prostate cancer treatment has confirmed findings in other published reports indicating that men living after prostate cancer treatment need better support from HCPs and more tailored and timely access to effective ED management. Results highlighted a lack of consensus over roles and responsibilities: there needs to be a clearly defined pathway for discussion and management of ED, starting from the planning stage of prostate cancer treatment.

There is an urgent need for better education regarding ED management to be offered to primary care, particularly regarding the importance of early sexual rehabilitation, and for more high-quality evidence to support the recovery of sexual function following prostate cancer treatment. v

FOOTNOTES

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Author contributions

AH and AD designed and administered the surveys, analysed the data and drafted the manuscript. IW and MK contributed to the study design, data interpretation and drafting of the manuscript. All authors edited the manuscript and gave final approval of the version to be published.

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Competing interests

None declared.

Data sharing statement

Due to the personal and sensitive nature of the survey data collected in this study, including substantial free-text answers, it is not ethically possible to make available the full dataset as this would compromise participants' anonymity and privacy.

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FIGURE LEGENDS

Figure 1. Level of confidence among (a-c) GPs and (d-f) practice nurses that their knowledge of prostate cancer, ED and treatment options for ED is sufficiently comprehensive/up-to-date to support men with prostate cancer.

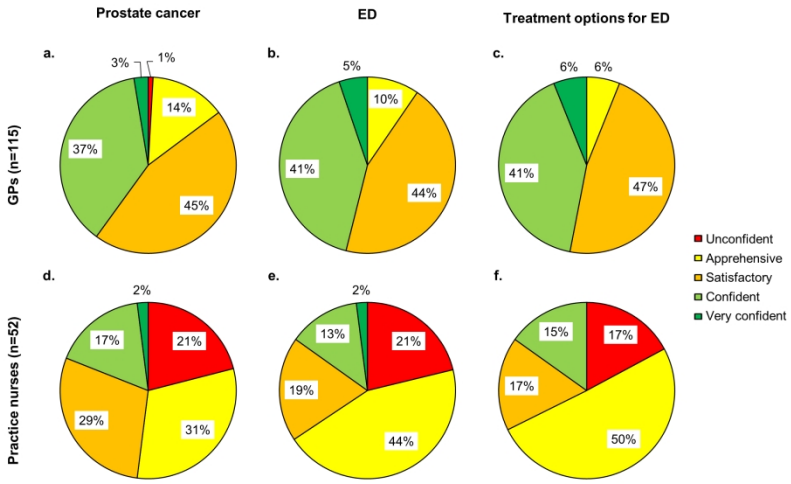
GPs were asked two separate questions about comprehensive knowledge and up-to-date knowledge. The data shown is for comprehensive knowledge. Practice nurses were asked a single question about comprehensive/up-to-date knowledge.

Figure 2. Roles and responsibilities of HCPs for the initiation, monitoring and follow-up of an ED management strategy according to (a) GPs, (b) practice nurses, (c) urologists and (d) CNSs.

HCPs could select more than one option from initiate (black), monitor (grey) or follow-up (white).

Figure 3. ED management strategies used after prostate cancer treatment by GPs (n=115) and urologists (n=50).

HCPs could select more than one option.



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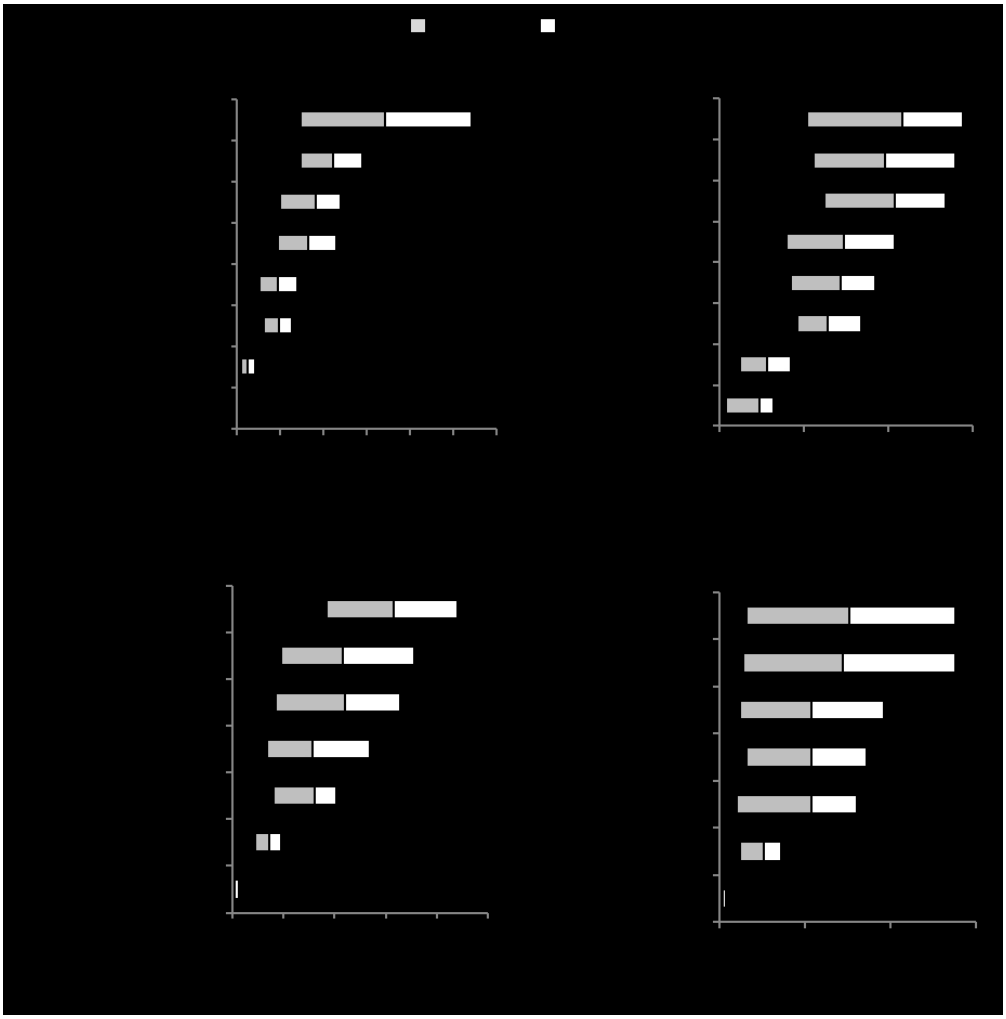
GPs were asked two separate questions about comprehensive knowledge and up-to-date knowledge. The data shown is for comprehensive knowledge. Practice nurses were asked a single question about comprehensive/up-to-date knowledge.

254x190mm (300 x 300 DPI)



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HCPs could select more than one option from initiate (black), monitor (grey) or follow-up (white).

156x157mm (150 x 150 DPI)

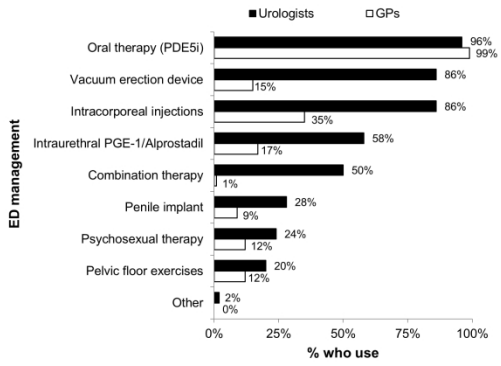

Figure 3. ED management strategies used after prostate cancer treatment by GPs (n=115) and urologists (n=50).

HCPs could select more than one option.

254x190mm (300 x 300 DPI)

SUPPLEMENTARY FILES

Supplementary File 1. Sociodemographic characteristics and treatment information of survey respondents with erectile dysfunction after prostate cancer treatment (n=546).

	Number of respondents	Percentage of respondents
Age (y)		
<50	9	2%
50-59	118	22%
60-69	280	51%
70-79	120	22%
≥80	19	3%
Total	**546**	**100%**
Country		
England	400	73%
Scotland	106	19%
Wales	37	7%
Northern Ireland	3	1%
Total	**546**	**100%**
Sexuality		
Heterosexual	513	94%
Bisexual	13	2%
Gay	17	3%
Total	**543**	**100%**
Relationship status		
Married/civil partnership	422	78%
Have a partner, but not living together	34	6%
Do not currently have a partner	36	7%
Living with partner but not married/in civil partnership	31	6%
Widowed	21	4%
Total	**544**	**100%**
Year of first treatment for prostate cancer		
pre 1995	3	1%
1995-1999	21	4%
2000-2004	55	10%
2005-2009	181	33%
2010-2014	286	52%
Total	**546**	**100%**
Number of prostate cancer treatments received		
1	356	66%
2	160	30%
3	26	5%
Total	**542**	**100%**

Percentages have been rounded to whole numbers.

Supplementary File 2. Treatments received for prostate cancer (n=546)

	Total	Surgery	RT+ADT	Other
Active surveillance*	**30 (5%)**	15**	2**	13 (8%)
Watchful waiting*	**19 (3%)**	6**	4**	9 (5%)
Chemotherapy	**7 (1%)**	n/a	n/a	7 (4%)
Cryotherapy	**6 (1%)**	n/a	n/a	6 (4%)
EBRT	**137 (25%)**	n/a	91 (77%)	46 (27%)
HIFU	**4 (1%)**	n/a	0	4 (2%)
ADT	**182 (33%)**	n/a	118 (100%)	64 (38%)
Brachytherapy (all)	**40 (7%)**	n/a	11 (9%)	29 (17%)
Permanent seed	*27 (5%)*	*n/a*	*5 (4%)*	*22 (13%)*
Temporary	*13 (2%)*	*n/a*	*6 (5%)*	*7 (4%)*
Radical prostatectomy (all)	**310 (57%)**	258 (100%)	n/a	52 (31%)
Standard laparoscopic	*102 (19%)*	*92 (36%)*	*n/a*	*10 (6%)*
Robotic-assisted laparoscopic	*73 (13%)*	*69 (27%)*	*n/a*	*4 (2%)*
Open	*135 (25%)*	*97 (38%)*	*n/a*	*38 (22%)*
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**

ADT = androgen deprivation therapy; EBRT = external beam radiotherapy; HIFU = high-intensity focused ultrasound; RT = radiotherapy (including brachytherapy)

Percentages in brackets are a percentage of each column, unless otherwise stated. Respondents could select more than one answer except if brachytherapy (all) or radical prostatectomy (all) was selected, then only one subtype could then be chosen.

"Total" All men who took part in the survey and reported ED following treatment

"Surgery alone" Men whose only radical treatment was radical prostatectomy

"RT+ADT alone" Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT

"Other" All men who received a treatment other than “surgery alone” or “RT + ADT alone”

* Includes patients who started on active surveillance/watchful waiting who went on to receive radical treatment.

** Data excluded from the percentage calculations.

Supplementary File 3. ED treatments received (n=521)

	Number of responses	% of respondents (n=521)
Viagra (sildenafil) 25mg	81	16%
Viagra (sildenafil) 50mg	105	20%
Viagra (sildenafil) 100mg	91	17%
Cialis (tadalafil) 5mg	110	21%
Cialis (tadalafil) 10mg	71	14%
Cialis (tadalafil) 20mg	152	29%
Levitra (vardenafil) 10mg	30	6%
Levitra (vardenafil) 20mg	53	10%
MUSE (i/u alprostadil) 125ug	23	4%
MUSE (i/u alprostadil) 250ug	31	6%
MUSE (i/u alprostadil) 500ug	21	4%
MUSE (i/u alprostadil) 1000ug	20	4%
Caverject 5mg	38	7%
Caverject 20mg	65	12%
Caverject 40mg	20	4%
Viridal Duo 10mg	7	1%
Viridal Duo 20mg	10	2%
Viridal Duo 40mg	9	2%
Vacuum erection device	170	33%
Pelvic floor exercises	104	20%
Sexual therapy	3	1%
Counselling	11	2%
Don't know	4	1%
None	108	21%

Respondents could select more than one answer.

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Management of erectile dysfunction after prostate cancer treatment – cross-sectional qualitative surveys of the perceptions and experiences of patients and healthcare professionals in the UK

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TITLE OF THE ARTICLE

Management of erectile dysfunction after prostate cancer treatment – cross-sectional qualitative surveys of the perceptions and experiences of patients and healthcare professionals in the UK

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ABSTRACT

Objectives: Erectile dysfunction (ED) is known to be a common consequence of radical treatment for prostate cancer (PCa) but is often under-reported and under-treated. This study aimed to explore how ED in PCa patients is managed in real-life clinical practice, from the perspective of patients and healthcare professionals (HCPs).

Design and setting: A UK-wide cross-sectional qualitative survey of men with ED after treatment for PCa which covered assessment and discussion of erectile function, provision of supportive care and satisfaction with management. Parallel qualitative surveys of primary and secondary HCPs were also conducted.

Results: Responses were received from 546 men with ED after PCa treatment, 167 primary (GPs and practice nurses) and 94 secondary care HCPs (urologists and urology Clinical Nurse Specialists). Survey findings revealed inadequate management of ED in primary care, particularly under-prescribing of effective management options. A fifth of men (21%) were not offered any ED management and a similar proportion (23%) were not satisfied with the way that HCPs addressed their ED concerns. There was poor communication between HCPs and men, including failure to initiate discussions about ED and/or involve partners, with 12% of men not told that ED was a risk factor of PCa treatment. These issues seemed to reflect poor access to effective ED management or services and lack of primary HCP confidence in managing ED, as well as confusion over roles and responsibilities among both HCPs and men.

Conclusions: This study confirms the need for better support for men from HCPs and more tailored and timely access to effective ED management after treatment for PCa. A clearly defined pathway is required for the discussion and management of ED, starting from the planning stage of PCa treatment. Improved adherence to ED management guidelines and better education and training for primary care HCPs are areas of priority.

ARTICLE SUMMARY: Strengths and limitations of this study

- This is the first UK study to survey the perceptions and experiences of men with erectile dysfunction after prostate cancer treatment and therefore adds considerable knowledge to the field.

- Also surveying primary and secondary HCPs on the same topics revealed additional unique challenges in management coordination for these men.

- Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received.

- The survey sample contained a higher proportion of younger patients than the prostate cancer population as a whole and compliance with ED treatment was not explored.

- The surveys were conducted before the availability of generic / over-the counter sildenafil and generic tadalafil.

INTRODUCTION

In 2018, 1.28 million men were diagnosed with prostate cancer worldwide, which represented 13% of all cancers diagnosed in men.[1,2] In the UK, prostate cancer is the most common cancer in men, with over 56,000 new cases diagnosed in 2018.[3] Radical treatments for prostate cancer include radical prostatectomy (RP), external beam radiotherapy (EBRT), brachytherapy, High Intensity Focused Ultrasound (HIFU) and androgen deprivation therapy (ADT).[4,5] Active surveillance is also offered as an option to men with low-risk, and sometimes intermediate-risk, localised prostate cancer.[4]

While effective in prolonging survival,[6] these treatments commonly induce erectile dysfunction (ED).[7–9] The UK-wide Life After Prostate Cancer Diagnosis (LAPCD) study examining patient-reported outcomes of over 30,000 prostate cancer survivors at 18-42 months after diagnosis recently reported that 81% of patients described their overall sexual function as poor or very poor.[10] By comparison, the prevalence of poor sexual function in the general population of men aged 60 and over is 33%.[11]

Typically, ED, accompanied by gradual structural changes in the penis, develops over a few months and up to 2-3 years after treatment and may be permanent. ADT may also cause loss of sexual interest, as well as more general symptoms such as fatigue, low mood, weight gain and decreased muscle mass. ED has been linked to loss of self-esteem, and depression,[12] and can significantly impair quality of life for both men and their partners.[7,8,10,13]

A wide range of treatments are available for the management of ED, including oral phosphodiesterase type 5 inhibitors (PDE5i), intracavernosal injections (ICI), intraurethral suppositories or ointment (alprostadil), vacuum erection devices (VED) and penile implants.[4,5,14] Nevertheless, ED remains an under-reported and often under-treated condition [15–18]. The LAPCD study reported that only 44% of men were offered intervention(s) to help with sexual function such as medications, devices or specialist services.[10] A recent review from a high-volume centre suggested that despite the advancements in surgical technique and post-operative care, erectile function outcomes after radical prostatectomy have not improved over the last decade and more efforts are needed to improve patient's care after radical prostatectomy.[19]

To address healthcare professionals' (HCP) concerns that no UK guidelines were available for the management of ED in prostate cancer patients, specific consensus guidelines for treating ED after prostatectomy [7] or radiotherapy/ADT [8] have been developed. These guidelines emphasise the importance of proactive early sexual rehabilitation post-prostatectomy, including patient education and pharmacological intervention, to minimise treatment-induced penile changes and to actively manage the impact of loss of sexual desire and delayed ED post-radiotherapy/ADT on men and their partners.

The aim of this study was to explore how ED after prostate cancer treatment is experienced, assessed and managed in a publicly-funded health care system, from the perspectives of both patients and HCPs. We conducted a UK-wide survey of men with ED after prostate cancer treatment and parallel surveys of primary and secondary HCPs, including GPs, practice nurses, urologists and urology Clinical Nurse Specialists (CNS).

METHODS

Study design and participants

An online qualitative cross-sectional survey of men experiencing ED after prostate cancer treatment was conducted between August 2014 and March 2015. The survey consisted of a maximum of 48 questions and participants were told it would take 10 – 15 minutes to complete. Survey questions (**Supplementary File 1**) explored the assessment and discussion of erectile function (EF) with HCPs and satisfaction with ED management. To recruit participants, a hyperlink to the open online survey was widely disseminated through Prostate Cancer UK's communication channels including electronic newsletters and social media. Paper versions of the survey were also provided upon request and these results were manually entered into the dataset.

Online qualitative cross-sectional surveys of GPs, practice nurses, urologists, and urology CNSs were conducted between October 2014 and January 2015. The primary care survey consisted of a maximum of 16 questions and the secondary care survey consisted of a maximum of 18 questions. All participants were told it would take 10 minutes to complete. Survey questions (**Supplementary File 1**) explored confidence regarding knowledge of prostate cancer and ED (primary HCPs only), discussions about potential side effects of prostate cancer treatment, how EF is assessed, the involvement of partners, ED management options and roles and responsibilities. Participants were invited via Doctors.net.uk and Nursing in Practice access panels, weighted on gender, age and location to be representative of the respective HCP populations.

Questions for both surveys were co-produced and piloted by men living with and after prostate cancer and HCPs, through virtual working groups and face-to-face workshops. Before beginning each survey, participants were informed of the approximate length of time to complete the survey, the purpose of the study, that their responses would be confidential and not used for any other purposes beyond this research study and contact details of the study team. Where appropriate, the online survey platform randomised the order that response options for a question were displayed, in order to reduce bias. Only completed questionnaires were included in the final dataset.

A STROBE checklist is provided as **Supplementary File 2**.

Statistical analysis

Data were analysed based on the number and percentage of respondents to each question. For the survey of men with ED after prostate cancer treatment, responses were grouped and analysed by type of prostate cancer treatment received. HCP data was already split by profession at the time of data collection. Data was then pooled to compare between professions.

Patient and public involvement statement

The Prostate Cancer UK 'Policy & Campaigns Forum', consisting of men living with and after prostate cancer, initially raised the issues around ED after prostate cancer treatment as a suggested area of work for Prostate Cancer UK to focus on. The Forum members were subsequently involved in the planning of the study, including development of the research questions and survey design.

RESULTS

Survey of men with ED after prostate cancer treatment

Respondent characteristics

Complete responses from 561 men with ED after prostate cancer were received (a self-selecting convenience sample). Responses from 15 men who had not received treatment in the UK were excluded, leaving a total of 546 respondents for analysis (**Table 1**). The number of responses per question ranged from 408 to 546 (75-100% response rate) due to respondents selecting they did not know the answer or that the question did not apply to them.

The mean respondent age was 65 years, with half (n=280/546; 51%) of the study sample aged between 60-69 years (**Table 1**). . Approximately half (n=286/546; 52%) of respondents had received their initial treatment for prostate cancer in the last 4 years. This sample closely resembles the prevalence of all prostate cancer patients alive in England at the end of 2015, with 50% living 0-5 years, 33% 5 – 10 years, 16% 10 – 15 years and 5% 15 – 21 years after diagnosis.[20] The majority (n=356/542; 66%) of respondents had received only one treatment for prostate cancer, while 30% (n=160) received two and 5% (n=26) three. The most common treatment was radical prostatectomy (n=310/546; 57%), either alone (n=258; 47%) or in combination with other treatment(s) (n=52; 10%). One-quarter of patients (n=137/546; 25%) received EBRT and one-third (n=182; 33%) received androgen deprivation therapy (ADT) (**Supplementary File 3**).

Table 1. Characteristics of survey respondents with erectile dysfunction after prostate cancer treatment (n=546)

Country	
England	400 (73%)
Scotland	106 (19%)
Wales	37 (7%)
Northern Ireland	3 (1%)
Total	**546 (100%)**
Age (y)	
<50	9 (2%)
50-59	118 (22%)
60-69	280 (51%)
70-79	120 (22%)
≥80	19 (3%)
Total	**546 (100%)**
Sexual orientation	
Heterosexual	513 (94%)
Gay	17 (3%)
Bisexual	13 (2%)
Total	**543 (100%)**
Relationship status	
Married/civil partnership	422 (78%)
Have a partner, but not living together	34 (6%)
Do not currently have a partner	36 (7%)
Living with partner but not married/in civil partnership	31 (6%)
Widowed	21 (4%)
Total	**544 (100%)**
Years since first treatment for prostate cancer	
20 and above	3 (1%)
15 – 19	21 (4%)
10 – 14	55 (10%)
5 - 9	181 (33%)
0 – 4	286 (52%)
Total	**546 (100%)**
Number of prostate cancer treatments received	
1	356 (66%)
2	160 (30%)
3	26 (5%)
Total	**542 (100%)**

Percentages have been rounded to whole numbers.

Men's experiences prior to prostate cancer treatment

Almost three-quarters of respondents (n=401/546; 73%) indicated that they had 'always'/'almost always' been able to get and keep an erection before their prostate cancer treatment with only 2% (n=10) stating they were not sexually active before treatment (**Table 2**).

Over one-third (n=191/525; 36%) reported that their consultant was the first HCP to question them about their EF before treatment, while another third (n=182; 35%) reported that no one had asked about this (**Table 2**). Less than 10% (n=48/546; 9%) of respondents had completed a pre-treatment standard questionnaire, such as the Sexual Health Inventory for Men (SHIM) [21] or International Index of Erectile Function (IIEF) [22]. Men who were to undergo prostatectomy were more likely to be asked to complete a questionnaire, compared to men who were to receive radiotherapy with ADT (14% versus 6%, respectively).

Most respondents (n=447/546; 82%) were told by their doctor or nurse that ED might be a side effect of their treatment, however 12% (n=68) were not told this information. This information was more likely to be given to men before a prostatectomy, compared to radiotherapy and ADT (91% versus 74%, respectively) (**Table 2**). For respondents with a partner (n=473), 70% (n=332) said their partners were involved in these discussions with their HCPs. The knowledge of possibly experiencing erection difficulties influenced the choice of prostate cancer treatment for 13% (n=74/546) of men.

Table 2. Men's experiences prior to prostate cancer treatment

How often were you [the patient] able to get and keep an erection before prostate cancer treatment? (n=546)				
	Total	**Surgery**	**RT+ADT**	**Other**
Almost always/always	**401 (73%)**	205 (79%)	75 (64%)	121 (71%)
Most times (>50%)	**64 (12%)**	21 (8%)	18 (15%)	25 (15%)
Sometimes (<50%)	**54 (10%)**	26 (10%)	13 (11%)	15 (9%)
Almost never/never	**14 (3%)**	4 (2%)	7 (6%)	3 (2%)
No sexual activity	**10 (2%)**	1 (0%)	3 (3%)	6 (4%)
Unsure	**3 (1%)**	1 (0%)	2 (2%)	0 (0%)
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**
Who asked the first questions about your [the patient's] erections before treatment? (n=525)				
	Total	**Surgery**	**RT+ADT**	**Other**
Your consultant	**191 (36%)**	123 (49%)	22 (20%)	46 (28%)
Your GP	**14 (3%)**	6 (2%)	2 (2%)	6 (4%)
Your Nurse	**35 (7%)**	17 (7%)	9 (8%)	9 (5%)
Your Partner	**4 (1%)**	1 (0%)	0 (0%)	3 (2%)
You [the patient]	**99 (19%)**	47 (19%)	19 (17%)	33 (20%)
No one	**182 (35%)**	55 (22%)	60 (54%)	67 (41%)
Total (% of total)	**525 (100%)**	**249 (47%)**	**112 (21%)**	**164 (31%)**
Did your [the patient's] doctor or nurse tell you [the patient] that erectile dysfunction might be a side effect of treatment? (n=546)				
	Total	**Surgery**	**RT+ADT**	**Other**
Yes	**447 (82%)**	235 (91%)	87 (74%)	125 (74%)
No	**68 (12%)**	11 (4%)	21 (18%)	36 (21%)
Unsure	**28 (5%)**	10 (4%)	9 (8%)	9 (5%)
ED not a side effect of the treatment I had	**3 (1%)**	2 (1%)	1 (1%)	0 (0%)
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**

Percentages in brackets are a percentage of each column, unless otherwise stated.

"Total"	All men who took part in the survey and reported ED following treatment
"Surgery"	Men whose only radical treatment was radical prostatectomy
"RT+ADT"	Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT
"Other"	All men who received a treatment other than “surgery” or “RT + ADT”

Men’s experiences after prostate cancer treatment

Following prostate cancer treatment, half (n=229/437; 52%) of men were asked about their EF by their HCP within 3 months (**Table 3**), most commonly by their consultant, and this rose to 69% (n=156) in the group that had prostatectomy. However, 29% (n=127) of all respondents said they had not been asked by any HCP about EF following prostate cancer treatment (**Table 3**). Almost a quarter (n=123/489; 23%) of men were not satisfied with the way that HCPs addressed their EF concerns.

Treatment for ED

Two-fifths of men (n=199/503; 40%) said they were offered ED treatment within 3 months of their prostate cancer treatment, with a further 19% (n=94) being offered treatment within 4-6 months. A fifth of men (n=110; 22%), said they were not offered any treatment (**Table 3**). Treatment was most commonly offered by a consultant (n=230/516; 45%) and usually in a urology department (n=181/503; 36%), GP surgery (n=120; 24%) or ED clinic (n=89; 18%).

ED management options men were offered for ED are shown in **Supplementary File 4** (n=521): most commonly they were offered 3 options (n=122/521; 29%). The most common treatments offered were sildenafil 25, 50 or 100mg (16%, 20%, 17%), VED (33%), tadalafil 5, 10 or 20mg (21%, 14%, 29%) and pelvic floor exercises (20%), mostly on NHS prescription. The most common treatments prescribed privately were also PDE5i and VED.

When asked whether they had any difficulty or delays in getting access to ED treatment, one-quarter (n=103/431; 25%) indicated experiencing such problems. These included issues with supply and availability such as ‘restricted availability due to limited prescriptions’, ‘pharmacies lacking stock’, ‘cost’ and ‘HCPs not being helpful/willing to prescribe/lacking knowledge’.

Table 3. Men’s experiences after prostate cancer treatment

How soon after prostate cancer treatment, if at all, did the consultant, GP or nurse ask whether your ability to get or keep an erection had been affected? (n=437)				
	Total	**Surgery**	**RT+ADT**	**Other**
≤3 months	**229 (52%)**	156 (69%)	29 (33%)	44 (35%)
4-6 months	**59 (14%)**	34 (15%)	7 (8%)	18 (14%)
7-12 months	**16 (4%)**	5 (2%)	4 (5%)	7 (6%)
>12 months	**6 (1%)**	1 (<1%)	1 (1%)	4 (3%)
Not at all	**127 (29%)**	29 (13%)	46 (53%)	52 (42%)
Total (% of total)	**437 (100%)**	**225 (51%)**	**87 (20%)**	**125 (29%)**
How long after prostate cancer treatment, if at all, were you offered treatment to help you get or keep an erection? (n=503)				
	Total	**Surgery**	**RT+ADT**	**Other**
<3 months	**199 (40%)**	128 (54%)	24 (23%)	47 (29%)
4-6 months	**94 (19%)**	53 (22%)	12 (11%)	29 (18%)
7-12 months	**38 (8%)**	20 (8%)	6 (6%)	12 (8%)
>12 months	**28 (6%)**	8 (3%)	12 (11%)	8 (5%)
Unsure	**34 (7%)**	10 (4%)	9 (8%)	15 (9%)

Not at all	**110 (22%)**	18 (8%)	43 (41%)	49 (30%)
Total (% of total)	**503 (100%)**	**237 (47%)**	**106 (21%)**	**160 (32%)**

Percentages in brackets are a percentage of each column, unless otherwise stated.

"Total" All men who took part in the survey and reported ED following treatment

"Surgery" Men whose only radical treatment was radical prostatectomy

"RT+ADT" Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT

"Other" All men who received a treatment other than “surgery” or “RT + ADT”

Monitoring of ED treatment

Over three quarters of respondents (n=374/484; 77%) said they were not asked to complete a questionnaire about their erections, such as the SHIM or IIEF, during ED treatment. When asked whether their prescribed ED treatment met their needs, only 32% (n=128/402) said ‘yes’, while 51% (n=204) said ‘no’ and 17% (n=70) were ‘unsure’. Approximately half of the respondents (n=298/546; 55%) reported having access to a CNS, with the remainder saying they did not have access, or were uncertain.

Survey of primary and secondary healthcare professionals

Respondent characteristics

Complete responses from 282 HCPs were received. 21 responses were excluded from the analysis due to duplicate entries, leaving a total of 261 HCPs in the analysis (115 GPs, 52 practice nurses (four of whom were nurse practitioners/advanced nurse practitioners), 50 urologists and 44 urology CNSs) (**Table 4**).

Table 4. Characteristics of primary and secondary HCP survey respondents (n=261)

	GPs	Practice nurses	Urologists	Urology CNSs
Country				
England	97 (84%)	45 (91%)	41 (82%)	38 (86%)
Scotland	10 (9%)	0 (0%)	4 (8%)	2 (5%)
Wales	5 (4%)	4 (6%)	4 (8%)	3 (7%)
Northern Ireland	3 (3%)	3 (3%)	1 (2%)	1 (2%)
Total	**115 (100%)**	**52 (100%)**	**50 (100%)**	**44 (100%)**
Gender				
Male	64 (62%)	Not asked	40 (80%)	Not asked
Female	39 (38%)		10 (20%)	
Total	**103 (100%)**		**50 (100%)**	
Age (y)				
Under 30	1 (1%)	Not asked	3 (6%)	Not asked
30 - 39	42 (41%)		19 (38%)	
40 - 49	35 (35%)		20 (40%)	
50 - 59	21 (20%)		8 (16%)	
60 or over	4 (4%)		0 (0%)	
Total	**103 (100%)**		**50 (100%)**	
Average number of prostate cancer patients seen per month				
0 - 9	85 (74%)	46 (90%)	3 (6%)	Not asked
10 – 19	11 (10%)	0	16 (32%)	
20 - 29	8 (7%)	0	10 (20%)	
30 – 39	10 (9%)	5 (10%)	10 (20%)	

40 – 49	0 (0%)	0	3 (6%)	
50 – 59	0 (0%)	0	2 (4%)	
60 – 69	0 (0%)	0	2 (4%)	
70 – 79	0 (0%)	0	0 (0%)	
80 – 89	1 (1%)	0	2 (4%)	
90 - 100	0 (0%)	0	2 (4%)	
Total	**115 (100%)**	**51 (100%)**	**50 (100%)**	

Percentages have been rounded to whole numbers.

Knowledge and confidence in ED management within primary care

GPs and practice nurses were asked how confident they were that their knowledge of prostate cancer, ED and treatment options for ED was sufficiently comprehensive and up-to-date to support men with prostate cancer. Most GPs indicated their knowledge as 'satisfactory'/'confident'/'very confident' for prostate cancer (n=98/115; 85%), for ED (n=104; 90%) and for treatment options for ED (n=108; 94%), compared to 48% (n=25/52), 34% (n=18) and 32% (n=17) of practice nurses, respectively, with the remainder stating they were 'apprehensive' or 'extremely unconfident' (**Figure 1**). When asked what would help to improve their confidence, the most common responses were 'training/education', and 'further information/literature/online resources'.

Discussions about ED

Only 26% of GPs (n=30/115) and 32% of practice nurses (n=16/51) said they 'usually'/'always' initiated a discussion about ED with men after prostate cancer treatment, with 29% (n=33) and 38% (n=19), respectively, saying they 'rarely'/'never' did so. This varied by gender for GPs, with 20% of male GPs (n=13/64) saying they 'never'/'rarely' initiated a discussion, compared with 44% of female GPs (n=17/39). The most common reasons GPs gave for not initiating a discussion about ED were that it 'wasn't a priority topic' or that 'the patient initiated the discussion'. However, 32% of GPs (n=37/115) said that men 'rarely'/'never' initiated a discussion about ED with them, while 25% of practice nurses (n=13/51) said the same. For GPs, this question varied less by gender than the previous question, with 33% of male GPs (n=21/64) saying patients 'never'/'rarely' initiated a discussion with them, compared with 41% of female GPs (n=16/39).

When secondary care HCPs were asked who was the most likely to initiate a discussion about ED, the majority of urologists (n=33/50; 61%) identified themselves, while for non-ED specialist CNSs (n=34) the most common first choice was the patient (n=12; 35%), followed closely by the urologist or urology/uro-oncology CNS (both n=11; 32%). A fifth of urologists (n=10/50; 20%) said that the duration of ADT would affect their decision whether to discuss ED with the patient, with the conversation more likely to take place for men on long-term ADT.

Involvement of partners in discussions about ED appeared to be more common in secondary care. 40% of urologists (n=20/50) versus only 13% of GPs (n=15/115) said they 'usually'/'always' involved men's partners in such discussions, while 24% of urologists (n=12/50) versus 60% of GPs (n=70/115) said they 'rarely'/'never' did so. Among the nurses surveyed, 65% of CNSs (n=28/43) said they involved partners, compared to only 12% of practice nurses (n=6/51).

Assessment of erectile function in secondary care

The majority of CNSs (34/44; 77%) and urologists (40/50; 80%) said they 'usually'/'always' performed a verbal baseline assessment of EF before treatment, with only 8% of urologists (n=4) saying they 'never'/'rarely' did this. Standardised questionnaires were used less frequently than verbal assessments by both urologists and CNSs. 30% (n=15/50) of urologists indicated that there were some patient groups they chose not to assess for baseline EF, for example if they were very elderly, had advanced disease or did not wish to be assessed. Other factors such as lifestyle, medication, comorbidities and relationships were also often included in the EF assessment.

Roles and responsibilities

Primary and secondary care HCPs were asked which HCPs or services they perceived as being involved in initiating, monitoring and following up on treatment for ED. The pattern of responses differed considerably between different HCP types, as shown in **Figure 2**. GPs and urologists had the most prominent role according to GPs and practice nurses, whereas urologists and CNSs identified themselves and dedicated ED services as playing the major roles. For CNSs, they identified themselves as having a greater focus on monitoring and follow-up than on management initiation.

Management of ED

In primary care, 39% of GPs (n=44/115) said that they 'usually'/'always' prescribed pharmacological management for ED among men affected by prostate cancer, while 51% (n=59) said 'sometimes', and 11% (n=12) 'rarely'/'never' did. Only 23% of practice nurses (n=12/52) said that they offered ED management.

A large majority of GPs (n=104/111; 94%) and urologists (42/50; 84%) used oral therapy (PDE5i) as their first line treatment for ED in prostate cancer patients. The PDE5i most commonly prescribed by GPs was sildenafil (93%), whereas urologists most commonly prescribed tadalafil (96%). Most GPs prescribed a dose of 4 tablets per month: only 38% of GPs, compared to 69% of urologists, prescribed daily low dose (5mg) tadalafil (the only daily PDE5i licensed for daily use).

GPs were much less likely than urologists to use second- or third-line treatments, including VED (15% vs 86%), intracorporeal injections (35% vs 86%), intraurethral PGE-1/alprostadil (17% vs 58%), penile implants (9% vs 28%), combination therapy (1% vs 50%), psychosexual therapy (12% vs 24%) and pelvic floor exercises (12% *vs* 20%) (**Figure 3**). A common reason for this would be that GPs would refer the patient to secondary or specialist care for these treatments. However, 41% of GPs (n=47/115) said they 'rarely'/ 'never' refer men with ED after prostate cancer treatment to secondary or specialist care.

Access to treatments

Treatments reported to be inaccessible to some GPs included penile implants (n=74/115; 64%), intracavernosal injections (n=51; 44%) and VEDs (n=48; 42%). Common reasons given were that these treatments were 'restricted to secondary care', 'not prescribed on the NHS' or 'a lack of training or expertise in their use'. Treatment access was less of an issue among secondary care HCPs: 56% of urologists (n=28) said that all ED treatments, including psychosexual therapy, were available to their patients.

DISCUSSION

Our survey of men explored the experiences of ED management after being treated for prostate cancer. In parallel surveys, we examined the knowledge and experience of primary and secondary HCPs in assessing such patients and their management strategies. Our findings indicated that, despite being at high risk from treatment-induced ED, many men were not treated according to recognised/available ED treatment guidelines available at the time of this study [14,23] and many were dissatisfied with their ED management. There was also an apparent mismatch between patient and HCP views on how post-treatment ED is managed in practice. It seems likely that, to some extent, HCPs' responses may have reflected their 'ideal' management rather than what actually took place in practice.

Management of ED in primary care

In particular, there seemed to be inadequate management of ED in primary care, including failure to implement early and structured strategies, combination ED management strategies and, in some instances, any ED treatment at all. These issues seemed to reflect restricted access to treatments and services and lack of confidence in managing ED. This suggests a need for better targeted training and education, particularly for practice nurses. Many GPs see relatively few prostate cancer patients, whereas practice nurses encounter men with ED more frequently, presumably when administering ADT injections or providing care for concomitant conditions, such as diabetes. In the UK there has been minimal under/postgraduate education in sexual medicine and human sexuality.[24,25] We also found a lack of assessment of EF before and after prostate cancer treatment, with low usage of formal/validated measurement instruments (e.g. IIEF, SHIM etc.) and no routine structured evaluation of ED management efficacy.

Communication between HCPs and patients

Communication between HCPs and patients was limited, with failures to initiate discussions about ED and/or involve partners in discussions. It was particularly worrying that 12% of men said they were not told that ED was a risk of prostate cancer treatment. Communication barriers between patients and HCPs are known to be a key factor in the under-reporting, and consequent under-treatment, of ED.[15,16] Understandably, HCPs may be hesitant to enquire into the personal aspects of men's lives, which may explain why in this study female GPs were less likely to initiate a conversation about ED after prostate cancer treatment, than male GPs. In addition, men themselves may be too embarrassed to raise the issue,[26,27] believe that ED is an inevitable result of ageing and/or not know which HCP to ask for help.[16] Factors such as advanced patient age may deter GPs from enquiring about sexual activity.[28,29] Although the men in our survey were not young (average age 65 years, with 25% aged ≥70 years), it was clear from their survey responses that sexual activity was still important to them. Other reports suggest that many men wish to continue sexual activity into their 8th and 9th decades.[30,31] Data from the diabetes setting has found patient embarrassment to be the most common reason for under-reporting of ED.[26] In male patients aged >30 years attending their physician, a brief patient questionnaire on EF was found to be an excellent aid for patients and physicians to prompt discussion about ED.[15] Patient reactions to the questionnaire included relief that the issue had been broached and the knowledge that help was available for ED. The Cancer Care Review (CCR), carried out by the GP or Practice Nurse within six months of the practice being notified an individual has a cancer diagnosis, is a component of the Recovery Package.[32] The CCR is a useful opportunity to discuss side effects of treatment, as part of a wider discussion. Despite the availability of CCR templates and guidance, CCRs are not always conducted in a systematic and consistent manner leading to variability in patient care and experience.[33]

As disease surveillance after treatment for prostate cancer generally occurs from 6 weeks post-treatment at 3-monthly intervals for at least 12 months in the UK,[4] it was disappointing that there were delays in initiating ED management within secondary care and poor communication with primary care. The necessary focus on disease surveillance in oncology clinics may result in low prioritisation of sexual difficulties. An observational study found that patients with prostate cancer were more likely to initiate a discussion about sexual function in the urology clinic than in the clinical oncology clinic (22% vs 4%), but nevertheless sexual concerns were not discussed at all in almost 50% of visits.[34]

Differences between HCP opinions

Importantly, we found considerable differences between HCP opinions regarding lead roles in the initiation, monitoring and follow-up of ED management: such confusion could easily lead to inadequate management and contradictory advice, as was evident from the men's survey results. These findings may reflect financial considerations, and, in the case of nurses, whether or not they have a prescribing role. The increased role of primary care in the follow-up of prostate cancer patients [35] requires unified management guidelines and support from Clinical Commissioning Groups

regarding GP prescribing of relevant treatments with local guidelines and shared care protocols. While urologists and specialist ED clinics were most commonly identified as being responsible for prescribing ED treatment, this management route inevitably leads to delays, due to the need for specialist referral and limited access to specialist ED clinics.

Specific consensus guidelines for treating ED after prostate surgery [7] and radiotherapy/ADT [8] have been developed. These guidelines emphasise the importance of proactive early ED management including patient education and pharmacological intervention, to minimise treatment-induced penile changes and the impact of loss of sexual desire and delayed ED on men and their partners.[7,8,36–38] They recommend daily and/or on-demand PDE5is as first-line treatment for patients who have undergone nerve-sparing prostatectomy.[7] PDE5is should be offered early after surgery, within the first month.[38,39] VEDs, alone or in combination with other modalities, may be used if other treatments have proved ineffective.

Access to treatments and specialist services

The finding in this study that many GPs did not prescribe treatments for ED is a matter for concern. Surprisingly, 44% of urologists did not have access to all ED treatments, despite NICE guidance.[4] NHS prescribing of PDE5 inhibitors is often limited to once-weekly use, which may not adequately support men's needs or specialist sexual rehabilitation programme aims.[40] 'Stinting' on effective treatments such as PDE5i can be a false economy, potentially resulting in treatment failure and the need for expensive secondary referrals.[17,18] It is hoped that the recent availability of reduced cost generic sildenafil and tadalafil, and the lifting of restrictions on its daily use, will allow more men with ED to receive early treatment.

Lack of access to specialist ED services is known to be a challenge for effective ED management, with support from nurses being identified as a significant factor impacting patient outcomes. Sexual counselling is known to contribute to better efficacy, patient acceptance of, and compliance with, other prescribed treatments for ED,[7] but was rarely offered in our survey. The National Prostate Cancer Audit (NPCA) 2014 annual report included results of an organisational audit of prostate cancer services in England and Wales. The audit showed 'sexual function services' to be available in 90% of NHS trusts in England and hospitals in Wales.[41] However, at the time, these data were inconsistent with findings from Freedom of Information requests submitted by Prostate Cancer UK in 2015 to 235 NHS health authorities across the UK to determine the availability of services (ED clinics, psychosexual clinics, and counselling/sexual therapy) and treatments (daily low-dose tadalafil, VEDs and penile implant surgery) for men with ED after prostate cancer treatment. These results indicated poor availability of ED clinics, with only 51% of areas stating they offered this service, with wide geographical variation.[42] The NPCA repeated their organisational audit in 2016/17 and 2018/19 and reported that 'sexual function services' were available in 100% of NHS trusts in England and Health Boards in Wales, either provided on site or by the specialist MDT site.[43,44] Despite the published availability of support services, this does not necessarily translate through to men being offered intervention(s), accepting these interventions(s) or that these intervention(s) are helpful. Although not yet proven to be effective, novel support approaches have been developed in a bid to tackle this problem such as the Movember Foundation's TrueNTH initiative online self-management programme which provides personalised self-management strategies to help improve sexual wellbeing after prostate cancer.[45]

Limitations of the study

Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received. Men and partners, physician and nurse's surveys were conducted separately and some response options differed between surveys, limiting direct comparisons. While HCPs generally answered all questions, many of the men's' survey questions were not answered and there were many 'unsure'/'don't know' or 'not applicable' responses. Men received a wide range of prostate cancer treatments: approximately half had undergone surgery (57%), but we were unable to determine how many had undergone nerve-sparing prostatectomy, since this question was not asked. Compliance with ED treatment was not explored. We did not conduct a separate analysis of data from gay and bisexual men, due to the small sample size, although recent data suggest that this group may have additional support needs than do heterosexual men.[46] For the survey of men with prostate cancer, a "convenience sample" was collected, which may limit generalisability of our results. The split by time since diagnosis was representative of all men living with and after prostate cancer in England as of 2015 however, the men in this study were younger than the prostate cancer population as a whole – with 25% aged 70 and over in this study, compared with 75% in the prostate cancer population.[20] This is most likely explained by the use of online resources to recruit men into the study. As already noted, the surveys were conducted before the availability of generic and over-the-counter sildenafil and generic tadalafil.

CONCLUSIONS

In conclusion, our survey of men experiencing ED after prostate cancer treatment has confirmed findings in other published reports indicating that men living after prostate cancer treatment need better support from HCPs and more tailored and timely access to effective ED management. Results highlighted a lack of consensus over roles and responsibilities: there needs to be a clearly defined pathway for discussion and management of ED, starting from the planning stage of prostate cancer treatment.

There is an urgent need for better education regarding ED management to be offered to primary care, particularly regarding the importance of early sexual rehabilitation, and for more high-quality evidence to support the recovery of sexual function following prostate cancer treatment.

FOOTNOTES

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Author contributions

AH and AD designed and administered the surveys, analysed the data and drafted the manuscript. IW and MK contributed to the study design, data interpretation and drafting of the manuscript. All authors edited the manuscript and gave final approval of the version to be published.

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Competing interests

None declared.

Data sharing statement

Due to the personal and sensitive nature of the survey data collected in this study, including substantial free-text answers, it is not ethically possible to make available the full dataset as this would compromise participants' anonymity and privacy.

Ethical approval statement

This study did not require an application for ethical approval, in line with the NHS Research Ethics Committee decision tool (http://www.hra-decisiontools.org.uk/ethics/). The study was assessed and approved by Prostate Cancer UK's Policy & Campaigns Forum, consisting of men living with and after prostate cancer, and Leadership Team. By completing the survey, respondents were consenting to be part of the study and were informed that their responses would be confidential and not used for any other purposes beyond this research study.

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FIGURE LEGENDS

Figure 1. Level of confidence among (a-c) GPs and (d-f) practice nurses that their knowledge of prostate cancer, ED and treatment options for ED is sufficiently comprehensive/up-to-date to support men with prostate cancer.

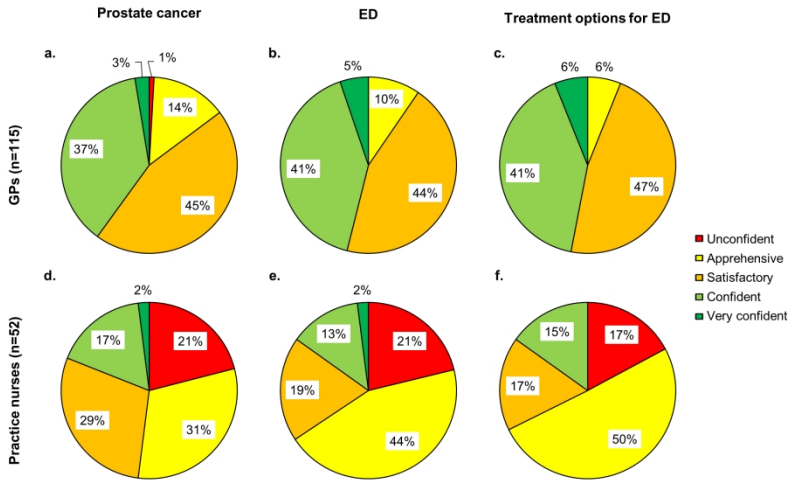
GPs were asked two separate questions about comprehensive knowledge and up-to-date knowledge. The data shown is for comprehensive knowledge. Practice nurses were asked a single question about comprehensive/up-to-date knowledge.

Figure 2. Roles and responsibilities of HCPs for the initiation, monitoring and follow-up of an ED management strategy according to (a) GPs, (b) practice nurses, (c) urologists and (d) CNSs.

HCPs could select more than one option from initiate (black), monitor (grey) or follow-up (white).

Figure 3. ED management strategies used after prostate cancer treatment by GPs (n=115) and urologists (n=50).

HCPs could select more than one option.



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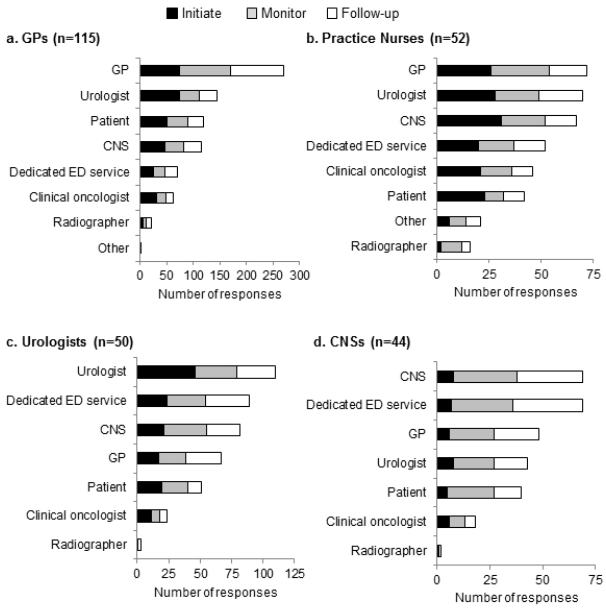

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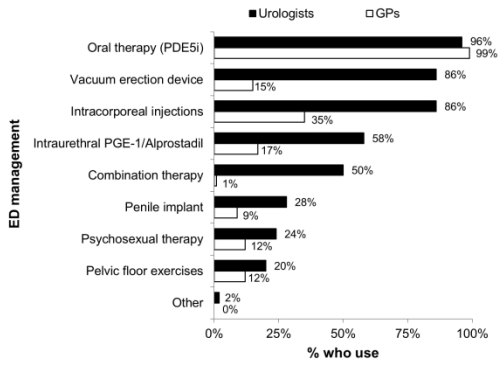

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HCPs could select more than one option.

254x190mm (300 x 300 DPI)

Supplementary File 1. Survey questions

Men with prostate cancer survey

Q1. Please tick the statement that best describes you:

I'm a man who's been treated for prostate cancer, and I have had trouble getting or keeping an erection after treatment *(the dataset used for analysis)*

I'm a man who's been treated for prostate cancer, but I have not had trouble getting or keeping an erection after treatment

Q2. How old are you?

Q3. When were you first treated for prostate cancer (year)?

Q4. When were you last treated for prostate cancer (year)? (please say if treatment is ongoing)

Q5. What is your relationship status?

Don't currently have a partner

Have a partner, but not living together

Living with a partner but not married or in a civil partnership

Married or in a civil partnership

Widowed

Q6. Do you consider yourself to be:

Heterosexual or straight

Gay

Bisexual

Q7. What type of prostate cancer treatment have you had (please select all that apply)?

Active surveillance

Watchful waiting

Surgery: open radical prostatectomy

Surgery: keyhole (laparoscopic) prostatectomy by hand

Surgery: keyhole (laparoscopic) prostatectomy using a robot

External beam radiotherapy

Permanent seed brachytherapy

Hormone therapy

Temporary brachytherapy

High intensity focused ultrasound (HIFU)

Cryotherapy

Chemotherapy

Unsure

Q8. Which hospital are / were you being treated in?

Q9. Where do you live (town or county)?

Q10a. Do, or did, you have access to a clinical nurse specialist (CNS)?

Yes

No

Unsure

***Q10b**. If yes, we would like to ask the CNS to complete a questionnaire about erectile dysfunction services.*

If you're willing to give us their contact details, please do so below:

Before prostate cancer treatment

Q11. Did the doctor or nurse ask about your erections before prostate cancer treatment?

Yes / No / Unsure

Q12. How often were you able to get and keep an erection before prostate cancer treatment?

Almost always or always

Most times (more than half the time)

Sometimes (about half the time)

A few times (less than half the time)

Almost never or never

No sexual activity

Unsure

Q13. Did you complete a questionnaire before prostate cancer treatment, for example the Sexual Health Inventory for Men (SHIM) or International Index of Erectile Function (IIEF) questionnaires?

Yes / No / Unsure

Q14. Did the doctor or nurse tell you that erectile dysfunction might be a side effect of treatment?

Yes / No / Unsure / Erectile dysfunction is not a side effect of the treatment I had

Q15. Did the possibility that you might experience erection difficulties influence the choice of prostate cancer treatment?

Yes / No / Unsure

Q16. Who asked the first questions about your erections before treatment?

The consultant

The GP

The nurse

Me

My partner

No one

Unsure

Other:

Q17. If you have a partner, were they involved in these discussions with your health professionals?

Yes / No / Unsure / Not applicable

Q18. If you have a partner, did you want them to be involved in these discussions?

Yes / No / Unsure / Not applicable

After prostate cancer treatment

Q19. After your prostate cancer treatment, which health professionals asked whether you had experienced any side effects?

The consultant

The GP

The nurse

No one asked

Unsure

Other:

Q20. How soon after prostate cancer treatment, if at all, did the consultant, GP or nurse ask whether your ability to get or keep an erection had been affected?

Q21. How soon after prostate cancer treatment, if at all, did you become concerned about your ability to get or keep an erection?

Q22. If you had concerns, were you satisfied with the way the health professional addressed your concerns about getting or keeping an erection?

Yes / No / Unsure / Not applicable

Q23. If you were not concerned about the ability to get or keep an erection immediately after treatment, did a health professional follow up on this question at a later date?

Yes / No / Unsure / Not applicable

Q24. If you did not experience erectile dysfunction immediately after treatment, did a health professional follow up on this question at a later date?

Yes / No / Unsure / Not applicable

Q25. If you have a partner, were they involved in these discussions with your health professionals?

Yes / No / Unsure / Not applicable

Q26. If you have a partner, did you want them to be involved in these discussions?

Yes / No / Unsure / Not applicable

Treatment for erection problems

Q27. How long after prostate cancer treatment, if at all, were you offered treatment to help get or keep an erection?

Q28. Who offered you treatment to help get or keep an erection?

The consultant

The GP

The nurse

No one offered treatment

Unsure

Other:

Q29. If you were given treatment to help get or keep an erection, were you asked if it was working, and if so, after how long?

Q30. If you have a partner, have you spoken to your partner about problems with your erections?

Yes / No / Unsure / Not applicable

Q31. Where are / were you being treated for problems with erections?

Urology department

Erectile dysfunction clinic

Psychosexual clinic

Counsellor/psychologist's office

Sex therapist's office

GP surgery

Didn't receive treatment

Unsure

Other:

Q32. Erection problems can be treated in a number of ways, and some treatments can be prescribed together. Which treatment(s) have you been offered on the NHS, or have you paid for privately, to help you get or keep an erection (please select all that apply)?

Viagra (sildenafil) tablets: 25 / 50 / 100mg

Cialis (tadalafil) tablets: 5 / 10 / 20mg

Levitra (vardenafil) tablets: 10 / 20mg

MUSE (Intra-urethral Alprostadil pellets): 125 / 250 / 500 / 1000ug

Caverject (Intra-cavernosal injections): 5 / 20 / 40mg

Viridal Duo (Intra-cavernosal injections): 10 / 20 / 40 mg

Vacuum erection device (penis pump)

Pelvic floor exercises

Sex therapy

Counselling

Don't know

None

Other (please describe)

Q33. For each of the treatments you've selected above, please tell us whether you combine(d) any of them (please give details):

Q34. For each of the treatments you've selected above, please tell us the number of times you tried them, and the length of time used (please also say if you are still using them):

Q35. What was your experience of each treatment or combination of treatments used? Was the treatment(s) helpful?

Q36. Have you had any difficulty or delays in getting access to the treatment(s)? (please explain)

Q37. Did the treatment(s) you were prescribed meet your needs?

Yes / No / Unsure / Not applicable

Q38. Did the doctor or nurse ask any questions about your erections, or ask you to complete a questionnaire while undergoing the treatments, for example the Sexual Health Inventory for Men (SHIM) or International Index of Erectile Function (IIEF) questionnaires?

Yes / No / Unsure / Not applicable

Q39. Have you been online to look for additional information and / or treatment? (if yes, please give details of the websites and any non-prescription treatment tried)

Q40. Are you still using any treatment to help get or keep an erection?

Yes / No / Unsure / Not applicable

Q41. How long have you been getting treatment for erection problems?

Q42. If you stopped treatment, please state why:

Q43. How have erection problems affected how you feel about yourself?

Q44. If applicable, what effect did, or do, your erection problems have on your relationship?

Q45. Is there anything that would have made your experience better? If so, what?

Q46. What is your opinion of the standard of care, information and support you have received from your GP, consultant and nurse?

Q47. Have you had any other sexual concerns or difficulties following treatment for prostate cancer? If so, please explain:

Q48. Have you sought help for any of these concerns or difficulties?

Yes, from the consultant

Yes, from the GP

Yes, from the nurse

Yes, from the counsellor

No

Unsure

Not applicable

Other:

Primary care survey (GPs and practice nurses)

S2 - Specialty confirmation
Are you a...
GP (1)
Practice Nurse (2)
Continence Adviser/Specialist (3)
Health visitor (4)
Other (5)
S2x Please specify 'Other'

S3 – Number of patients
In a three month period, on average how many patients will you see with a diagnosis of prostate cancer?
Please state the total number of patients, not individual consultations

D1 – Gender (GPs)
Are you...
Male (1)
Female (2)

D2 – Age (GPs)
Are you...
Under 30 (1)
30 - 39 (2)
40 - 49 (3)
50 - 59 (4)
60 or over (5)

D3 – Practice location (GPs)
Is your practice based in a...
Rural area (1)
Urban area (2)
Semi-rural area (3)
Suburban area (4)
Other (5)

D4 - Region
Whereabouts are you currently practising?
[Select from a list of UK regions and devolved nations]
Retired (14)
Not practising in the UK (15)

D5 – CCG
Which Clinical Commissioning Group do you primarily work in?
[Select from a list]
Other (212)

Q2 - Frequency
Thinking of the consultations for patients with prostate cancer, in an average month, how often would you expect to see any patient with prostate cancer?
All consultations, not individual patients.

Q3 - ED Discussion initiations
In relation to patients who have been diagnosed with/treated for prostate cancer, how often do you initiate a discussion about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q3b - Follow up for regular initiation of ED discussion
You indicated that you [show answer from above] initiate a discussion about ED, could you please explain when and how the conversation is initiated in the treatment pathway?

Q3c - Follow up for non- initiation of ED discussion

You indicated that you [show answer from above] initiate a discussion about ED, could you please explain why this conversation is [show answer from above] initiated?

Q4 - ED Patient initiations
How often do prostate cancer patients initiate a discussion with you about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q5 - ED Partner discussions
How often do you involve the partner of prostate cancer patients in discussions about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q6 - Wider treatment
In the treatment of prostate cancer more widely, who would you expect to initiate, monitor and follow-up an ED management strategy?
Please check all that apply.
Patient (1)
Urologist (2)
Clinical oncologist (3)
Urology/uro-oncology nurse specialist (4)
Dedicated ED service (5)
Radiographer (6)
GP (7)
Other (please state) (8)

Q7 - Point in pathway for ED discussion
At what point(s) in the patient pathway would you expect a discussion regarding ED to normally take place?
Please check all that apply.
Not routinely discussed (1)
At diagnosis of prostate cancer (2)
Prior to surgery (3)
Prior to radiotherapy (4)
Prior to initiation of ADT (5)
Any time during treatment (6)
After treatment/during follow up (7)
Other (please state) (8)
Don't know (9)

Q8 - Prostate cancer knowledge
Please indicate how confident you are in relation to the following statements regarding your knowledge of prostate cancer.
Extremely unconfident (1)
Apprehensive (2)
Satisfactory (3)
Confident (4)
Very confident (5)

I am confident that my knowledge of prostate cancer is sufficiently comprehensive to support men with prostate cancer (1)

I am confident that my knowledge of prostate cancer is sufficiently up to date to support men with prostate cancer (2)

Q8a - Follow up for 'comprehensive'
You indicated that you are [show answer from above] that your knowledge of prostate cancer is sufficiently comprehensive to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q8b - Follow up for 'up to date'
You indicated that you are [show answer from above] that your knowledge of prostate cancer is sufficiently up to date to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q9 - ED knowledge
Please indicate how confident you are in relation to the following statements regarding your knowledge of ED.
Extremely unconfident (1)
Apprehensive (2)
Satisfactory (3)
Confident (4)
Very confident (5)

I am confident that my knowledge of ED is sufficiently comprehensive to support men with prostate cancer (1)

I am confident that my knowledge of ED is sufficiently up to date to support men with prostate cancer (2)

Q9a - Follow up for 'comprehensive'
You indicated that you are [show answer from above] that your knowledge of ED is sufficiently comprehensive to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q9b - Follow up for 'up to date'
You indicated that you are [show answer from above] that your

knowledge of ED is sufficiently up to date to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q10 - ED treatment options knowledge
Please indicate how confident you are in relation to the following statements regarding your knowledge of treatment options for ED.
Extremely unconfident (1)
Apprehensive (2)
Satisfactory (3)
Confident (4)
Very confident (5)

I am confident that my knowledge of the treatment options for ED is sufficiently comprehensive to support men with prostate cancer (1)

I am confident that my knowledge of the treatment options for ED is sufficiently up to date to support men with prostate cancer (2)

Q10a - Follow up for 'comprehensive'
You indicated that you are [show answer from above] that your knowledge of the treatment options for ED is sufficiently comprehensive to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q10b - Follow up for 'up to date'
You indicated that you are [show answer from above] that your knowledge of the treatment options for ED is sufficiently up to date to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q11 - Manage ED
In relation to prostate cancer patients, do you prescribe treatment for ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q11a - Follow up
You indicated that you [show answer from above] prescribe treatment for ED. Please explain why that is.
Please answer as fully as possible

Q12 - ED treatments
Please indicate which of the following treatments are used by you or by other doctors in your practice for managing treatment of ED in prostate cancer patients.
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q13 – First-line treatment
Which of the treatments used by you or by other doctors in your practice is your/their first line choice for managing ED in prostate cancer patients?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q13a - Oral treatment details
You said that you or other doctors in your practice typically use oral therapy in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drug:
Dose:
Frequency:
Comments:

Q13b - Combination treatment details
You said that you or other doctors in your practice typically use combination therapies in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drugs:
Dose:
Frequency:
Comments:

Q14 - Options not available
Please indicate if any of the following treatments are not accessible at your practice.
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)
None of the above - all are available (10)

Q14a - Options not available reasons
You indicated that the following treatments are not accessible at your practice. Please explain why they are not available.
Please answer as fully as possible.

Q15 - Ideal first-line treatment
Assuming all treatment options were available to you, what would be your first line of treatment?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)
None of the above - all are available (10)

Q16 - Referral
Do you refer prostate cancer patients with ED on to secondary or specialist care?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q16a - Why not referred
You indicated that you never refer prostate cancer patients with ED on to secondary or specialist care. Please explain why that is.
Please answer as fully as possible

Q16b - To whom referred
You indicated that you refer prostate cancer patients with ED on to secondary or specialist care. Please indicate where these referrals are made.
Please select all that apply
ED specialist (1)
Sexual therapist (2)
Urologist (3)
Other (please state) (4)

Q16c – Most common referral
You indicated that you make referrals to the following specialists. Please select the specialist where you make the most referrals.
Please select one option
ED specialist (1)
Sexual therapist (2)
Urologist (3)
Other (please state) (4)

Secondary care survey (urologists and CNSs)

Please choose the option that is most applicable to you:

I specialise in erectile dysfunction (e.g. urologist specialising in ED, sexual advisor/therapist)

I specialise in urology (e.g. urologist not specialising in ED, urology nurse)

S2 – Specialty (urologists)
Which of the following best describes your specialty?
Please select one option
Urology (1)
Oncology (2)
Other (please specify) (3)

S3 – Number of patients (urologists)
In a three month period, on average how many patients will you see with a diagnosis of prostate cancer?
Please state the total number of patients, not individual consultations

S4 – Seniority (urologists)
Which of the following best describes your seniority?
Please select one option
Consultant (1)
Associate Specialist (2)
Staff Grade / Specialty Doctor (3)
Clinical Research Fellow (4)
Specialty Trainee / Registrar Years 5+ (5)
Specialty Trainee / Registrar Years 3-4 (6)
Specialty Trainee / Registrar Years 1-2 (7)
FD2 (8)
FD1 (9)
Other (please specify) (10)

D1 – Gender (urologists)
Are you...
Male (1)
Female (2)

D2 – Age (urologists)
Are you...
Under 30 (1)
30 - 39 (2)
40 - 49 (3)
50 - 59 (4)
60 or over (5)

D3 – Region (urologists)
Whereabouts are you currently practising?
[Select from a list of UK regions and devolved nations]
Retired (14)
Not practising in the UK (15)

D4 - Trust/health board (urologists)
In which trust do you primarily work?
[Select from a list]
Other (204)
Retired (234)

Q1 – Initiate discussion (urologists)
Thinking of the consultations for patients with prostate cancer, who would be most likely to initiate a discussion about ED?
Please select all that apply
Patient (1)
Urologist (2)
Clinical Oncologist (3)
Urology/uro-oncology nurse specialist (4)
Radiographer (5)
GP (6)
Other (please state) (7)

Q2 - Ranking Initiate discussion (urologists)
From the list below, please rank your choices in order of likelihood to initiate a discussion about ED.
Please enter 1 for most likely, 2 for second, 3 for third etc.
Patient (1)
Urologist (2)
Clinical Oncologist (3)
Urology/uro-oncology nurse specialist (4)
Radiographer (5)
GP (6)
Other (7)

Q2a - Initiate discussion follow up (urologists)
You indicated that the [show answer from above] was most likely to initiate a discussion about ED.
Can you please explain why the discussion is most likely to be initiated by the [show answer from above]?
Please answer as fully as possible

Q3 – Pathway (urologists)
Thinking about patients with prostate cancer, where in the patient pathway would you expect a discussion about ED to take place?
Please select all that apply
Not routinely discussed (1)
Prior to initiation of ADT (2)
Prior to radiotherapy (3)
Prior to surgery (4)
After treatment / during follow up (5)
Any time during treatment (6)
Other (please state) (7)

Q4 - ED Discussion initiations (urologists)
How often do you involve the partner of prostate cancer patients in discussions about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Assessment

Q5 - EF Baseline
Do you perform any baseline assessment of erectile function (EF) before treatment for prostate cancer?
Please select one option per row, apart from the 'Other' row if you don't need to specify any other baseline assessment.
Never (1) / Rarely (2) / Sometimes (3) / Usually (4) / Always (5)
For:
Verbal assessment (1)
IIEF (2)
IIEF-5 (3)
EDITS (4)
Other (Please state) (5)

Q5a - EF Baseline follow up
Please provide any additional comments regarding the use of [show answer from above] in assessing baseline EF before treatment for prostate cancer.

Q6 - No EF Baseline
Are there any patient groups you choose NOT to baseline assess for EF?
Yes (1)
No (2)

Q6a - NO EF baseline groups
Please specify the patient groups you choose NOT to baseline assess for EF.
Please use a separate text box for each group.

Q6b - No EF Baseline rationale
You said that you choose NOT to baseline assess the groups below for EF. Could you please explain why that is?
Please answer as fully as possible

Q7 - ADT
Would the duration of intended androgen deprivation therapy (ADT) affect your decision to discuss ED?
Yes (1)
No (2)

Q7a - ADT follow up
You said that the duration of intended androgen deprivation therapy (ADT) would affect your decision to discuss ED. Could you please explain why this is?
Please answer as fully as possible

Q8 - Assessment of impact on EF
In the context of prostate cancer, do you make an assessment of the impact of any of the following factors upon EF?
Please select all that apply
General lifestyle (1)
Medication(s) (2)
Cardiac Disease status (3)
Metabolic status / Diabetes (4)

Co-morbidities (5)
Psychological factors (6)
Relationship factors (7)
Other (Please state) (8)
None of the above (9)

Q9 - Discussion of impact on EF
Of the factors that you assess the impact of upon EF in prostate cancer patients, how often do you discuss these with the patient?
Please select one option per row
For the answer options above:
Never (1) / Rarely (2) / Sometimes (3) / Usually (4) / Always (5)

Q10 - Testosterone measurement
How often do you measure testosterone levels in men with prostate cancer?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q10a - Testosterone follow up
You said that you [show answer from above] measure testosterone levels in men with prostate cancer. Could you please explain what circumstances prompt this measurement?
Please answer as fully as possible

Referral

Q11 – Referrals (ED specialists)
How is a patient typically referred to your service (by who, when etc)?

Q12 - ED services offered (non-ED specialists)
What type(s) of ED support services are available for your patients?
Please select all that are available
An ED clinic (1)
VCD (Vacuum Constriction Device) demonstrations (2)
Psychological support (3)
Other (Please state) (4)
No ED support services are available (5)

Q12a - ED Clinic details (non-ED specialists)
Please give details of the ED clinic available for your patients
Please answer as fully as possible
Staffing, e.g. nurse specialist:
Frequency, e.g. weekly:
Support available, e.g. Counselling, sexual therapist, VCD demonstrations:

Q12b - Referral to ED support (non-ED specialists)
What proportion of patients with prostate cancer do you refer to ED support?
Please enter a percent of patients referred to ED support

Q12c - Referral to ED support – comments (non-ED specialists)
Please provide any additional comments about referrals to ED support, in particular groups of patients to whom this is applicable, and referral pathways which you follow
Please answer as fully as possible
Patient groups: (1)
Referral pathways: (2)

Q12d - NO ED Support (*non-ED specialists*)
You said that you do not have any ED support service available for your patients, could you please explain why not?
Please answer as fully as possible

Management & treatment strategies

Q13 - Wider treatment
In the treatment of prostate cancer more widely, who would you expect to initiate, monitor and follow-up an ED management strategy?
Please check all that apply.
Patient (1)
Urologist (2)
Clinical oncologist (3)
Urology/uro-oncology nurse specialist (4)
Dedicated ED service (5)
Radiographer (6)
GP (7)
Other (please state) (8)

Q14 - Assessment of ED at follow up
For patients with prostate cancer, do you personally assess and discuss ED at follow-up appointments?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q14a - Lead follow up ED discussion
You said that you [show answer from above] assess and discuss ED at follow-up appointments. Who would normally lead the discussion?
Please select all that apply
Yourself (1)
Urologist (2)
Specialist Nurse (3)
Patient (4)
Oncologist (5)
Other (Please state) (6)

Q15 - Treatment Options
For prostate cancer patients which of the following treatment options for ED do you typically use?
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q15a - Oral treatment details
You said that you typically use oral therapy in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drug:
Dose:
Frequency:
Comments:

Q15b - Combination treatment details
You said that you typically use combination therapies in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drugs:
Dose:
Frequency:
Comments:

Q16 – Preference of treatment available
Of the treatment options for ED typically in use, which is your personal preference?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q17 - Options not available
Please indicate if any of the following treatments for ED are not accessible to your patients.
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)
None of the above - all are available (10)

Q18 - Ideal first-line treatment
Assuming all treatment options were available to you, what would be your first line of treatment for ED?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)

Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Supplementary File 2. STROBE Statement - checklist of items that should be included in reports of ***cross-sectional studies***

	Item No.	Recommendation	Page No.
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	4
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	4
Study size	10	Explain how the study size was arrived at	4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	4
		(*b*) Describe any methods used to examine subgroups and interactions	4
		(*c*) Explain how missing data were addressed	4

		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5, 9
		(b) Give reasons for non-participation at each stage	
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	5, 9
		(b) Indicate number of participants with missing data for each variable of interest	5 - 11
Outcome data	15*	Report numbers of outcome events or summary measures	5 - 11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	5 - 11
		(*b*) Report category boundaries when continuous variables were categorized	5 - 11
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	5 - 11
Discussion			
Key results	18	Summarise key results with reference to study objectives	11, 12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12, 13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11, 12, 13

Generalisability	21	Discuss the generalisability (external validity) of the study results	11, 12, 13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Supplementary File 3. Treatments received for prostate cancer (n=546)

	Total	Surgery	RT+ADT	Other
Active surveillance*	**30 (5%)**	15**	2**	13 (8%)
Watchful waiting*	**19 (3%)**	6**	4**	9 (5%)
Chemotherapy	**7 (1%)**	n/a	n/a	7 (4%)
Cryotherapy	**6 (1%)**	n/a	n/a	6 (4%)
EBRT	**137 (25%)**	n/a	91 (77%)	46 (27%)
HIFU	**4 (1%)**	n/a	0	4 (2%)
ADT	**182 (33%)**	n/a	118 (100%)	64 (38%)
Brachytherapy (all)	**40 (7%)**	n/a	11 (9%)	29 (17%)
Permanent seed	*27 (5%)*	*n/a*	*5 (4%)*	*22 (13%)*
Temporary	*13 (2%)*	*n/a*	*6 (5%)*	*7 (4%)*
Radical prostatectomy (all)	**310 (57%)**	258 (100%)	n/a	52 (31%)
Standard laparoscopic	*102 (19%)*	*92 (36%)*	*n/a*	*10 (6%)*
Robotic-assisted laparoscopic	*73 (13%)*	*69 (27%)*	*n/a*	*4 (2%)*
Open	*135 (25%)*	*97 (38%)*	*n/a*	*38 (22%)*
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**

ADT = androgen deprivation therapy; EBRT = external beam radiotherapy; HIFU = high-intensity focused ultrasound; RT = radiotherapy (including brachytherapy)

Percentages in brackets are a percentage of each column, unless otherwise stated. Respondents could select more than one answer except if brachytherapy (all) or radical prostatectomy (all) was selected, then only one subtype could then be chosen.

"Total" All men with ED after prostate cancer treatment

"Surgery" Men whose only radical treatment was radical prostatectomy

"RT+ADT" Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT

"Other" All men who received a treatment other than “surgery” alone or “RT + ADT” alone

* Includes patients who started on active surveillance/watchful waiting who went on to receive radical treatment.

** Data excluded from the percentage calculations.

Supplementary File 4. Treatments received for ED (n=521)

	Number of responses	% of respondents
Viagra (sildenafil) 25mg	81	16%
Viagra (sildenafil) 50mg	105	20%
Viagra (sildenafil) 100mg	91	17%
Cialis (tadalafil) 5mg	110	21%
Cialis (tadalafil) 10mg	71	14%
Cialis (tadalafil) 20mg	152	29%
Levitra (vardenafil) 10mg	30	6%
Levitra (vardenafil) 20mg	53	10%
MUSE (i/u alprostadil) 125ug	23	4%
MUSE (i/u alprostadil) 250ug	31	6%
MUSE (i/u alprostadil) 500ug	21	4%
MUSE (i/u alprostadil) 1000ug	20	4%
Caverject 5mg	38	7%
Caverject 20mg	65	12%
Caverject 40mg	20	4%
Viridal Duo 10mg	7	1%
Viridal Duo 20mg	10	2%
Viridal Duo 40mg	9	2%
Vacuum erection device	170	33%
Pelvic floor exercises	104	20%
Sexual therapy	3	1%
Counselling	11	2%
Don't know	4	1%
None	108	21%

Respondents could select more than one answer.

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Management of erectile dysfunction after prostate cancer treatment – cross-sectional surveys of the perceptions and experiences of patients and healthcare professionals in the UK

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TITLE OF THE ARTICLE

Management of erectile dysfunction after prostate cancer treatment – cross-sectional surveys of the perceptions and experiences of patients and healthcare professionals in the UK

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ABSTRACT

Objectives: Erectile dysfunction (ED) is known to be a common consequence of radical treatment for prostate cancer (PCa) but is often under-reported and under-treated. This study aimed to explore how ED in PCa patients is managed in real-life clinical practice, from the perspective of patients and healthcare professionals (HCPs).

Design and setting: A UK-wide cross-sectional survey of men with ED after treatment for PCa which covered assessment and discussion of erectile function, provision of supportive care and satisfaction with management. Parallel surveys of primary and secondary HCPs were also conducted.

Results: Responses were received from 546 men with ED after PCa treatment, 167 primary (GPs and practice nurses) and 94 secondary care HCPs (urologists and urology Clinical Nurse Specialists). Survey findings revealed inadequate management of ED in primary care, particularly under-prescribing of effective management options. A fifth of men (21%) were not offered any ED management and a similar proportion (23%) were not satisfied with the way that HCPs addressed their ED concerns. There was poor communication between HCPs and men, including failure to initiate discussions about ED and/or involve partners, with 12% of men not told that ED was a risk factor of PCa treatment. These issues seemed to reflect poor access to effective ED management or services and lack of primary HCP confidence in managing ED, as well as confusion over roles and responsibilities among both HCPs and men.

Conclusions: This study confirms the need for better support for men from HCPs and more tailored and timely access to effective ED management after treatment for PCa. A clearly defined pathway is required for the discussion and management of ED, starting from the planning stage of PCa treatment. Improved adherence to ED management guidelines and better education and training for primary care HCPs are areas of priority.

ARTICLE SUMMARY: Strengths and limitations of this study

- This is the first UK study to survey the perceptions and experiences of men with erectile dysfunction after prostate cancer treatment and therefore adds considerable knowledge to the field.

- Also surveying primary and secondary HCPs on the same topics revealed additional unique challenges in management coordination for these men.

- Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received.

- The survey sample contained a higher proportion of younger patients than the prostate cancer population as a whole and compliance with ED treatment was not explored.

- The surveys were conducted before the availability of generic/over-the counter sildenafil and generic tadalafil.

INTRODUCTION

In 2018, 1.28 million men were diagnosed with prostate cancer worldwide, which represented 13% of all cancers diagnosed in men.[1,2] In the UK, prostate cancer is the most common cancer in men, with over 56,000 new cases diagnosed in 2018.[3] Risk factors for prostate cancer include increasing age [4], a family history of the disease in a first-degree relative [5–7], body weight [8] and ethnicity - 1 in 4 Black men will be diagnosed with prostate cancer in their lifetime in England, twice the risk of White men (1 in 8) [9].

Radical treatments for prostate cancer include radical prostatectomy (RP), external beam radiotherapy (EBRT), brachytherapy, High Intensity Focused Ultrasound (HIFU) and androgen deprivation therapy (ADT).[10,11] Active surveillance is also offered as an option to men with low-risk, and sometimes intermediate-risk, localised prostate cancer.[10]

While effective in prolonging survival,[12] these treatments commonly induce erectile dysfunction (ED).[13–15] The UK-wide Life After Prostate Cancer Diagnosis (LAPCD) study, examining patient-reported outcomes of over 30,000 prostate cancer survivors at 18-42 months after diagnosis, recently reported that 81% of patients described their overall sexual function as poor or very poor.[16] By comparison, the prevalence of poor sexual function in the general population of men aged 60 and over is 33%.[17]

Typically, ED, accompanied by gradual structural changes in the penis, develops over a few months and up to 2-3 years after treatment and may be permanent. ADT may also cause loss of sexual interest, as well as more general symptoms such as fatigue, low mood, weight gain and decreased muscle mass. ED has been linked to loss of self-esteem and depression[18] and can significantly impair quality of life for both men and their partners.[13,14,16,19]

A wide range of treatments are available for the management of ED, including oral phosphodiesterase type 5 inhibitors (PDE5is), intracavernosal injections (ICI), intraurethral suppositories or ointment (alprostadil), vacuum erection devices (VED) and penile implants.[10,11,20] Nevertheless, ED remains an under-reported and often under-treated condition.[21–24] The LAPCD study reported that only 44% of men were offered intervention(s) to help with sexual function such as medications, devices or specialist services.[16] A recent review from a high-volume centre suggested that despite the advancements in surgical technique and post-operative care, erectile function outcomes after radical prostatectomy have not improved over the last decade and more efforts are needed to improve patient's care after radical prostatectomy.[25]

To address healthcare professionals' (HCP) concerns that no UK guidelines were available for the management of ED in prostate cancer patients, specific consensus guidelines for treating ED after prostatectomy [13] or radiotherapy/ADT [14] have been developed. These guidelines emphasise the importance of proactive early sexual rehabilitation post-prostatectomy, including patient education and pharmacological intervention, to minimise treatment-induced penile changes and to actively manage the impact of loss of sexual desire and delayed ED post-radiotherapy/ADT on men and their partners.

The aim of this study was to explore how ED after prostate cancer treatment is experienced, assessed and managed in a publicly-funded health care system, from the perspectives of both patients and HCPs. We conducted a UK-wide survey of men with ED after prostate cancer treatment and parallel surveys of primary and secondary HCPs, including GPs, practice nurses, urologists and urology Clinical Nurse Specialists (CNS).

METHODS

Study design and participants

An online cross-sectional survey of men experiencing ED after prostate cancer treatment was conducted between August 2014 and March 2015. The survey consisted of a maximum of 48 questions and participants were told it would take 10 – 15 minutes to complete. Survey questions (**Supplementary File 1**) explored the assessment and discussion of erectile function (EF) with HCPs and satisfaction with ED management. To recruit participants, a hyperlink to the open online survey was widely disseminated through Prostate Cancer UK's communication channels including electronic newsletters and social media. Paper versions of the survey were also provided upon request and these results were manually entered into the dataset.

Online cross-sectional surveys of GPs, practice nurses, urologists, and urology CNSs were conducted between October 2014 and January 2015. The primary care survey consisted of a maximum of 16 questions and the secondary care survey consisted of a maximum of 18 questions. All participants were told it would take 10 minutes to complete. Survey questions (**Supplementary File 1**) explored confidence regarding knowledge of prostate cancer and ED (primary HCPs only), discussions about potential side effects of prostate cancer treatment, how EF is assessed, the involvement of partners, ED management options and roles and responsibilities. Participants were invited via Doctors.net.uk and Nursing in Practice access panels, weighted on gender, age and location to be representative of the respective HCP populations.

Questions for both surveys were co-produced and piloted with men living with and after prostate cancer and HCPs, through virtual working groups and face-to-face workshops. Before beginning each survey, participants were informed of the approximate length of time to complete the survey, the purpose of the study, that their responses would be confidential and not used for any other purposes beyond this research study and contact details of the study team. Where appropriate, the online survey platform randomised the order that response options for a question were displayed in order to reduce bias. Only completed questionnaires were included in the final dataset.

A STROBE checklist is provided as **Supplementary File 2**.

Statistical analysis

Data were analysed based on the number and percentage of respondents to each question. For the survey of men with ED after prostate cancer treatment, responses were grouped and analysed by type of prostate cancer treatment received. HCP data was already split by profession at the time of data collection. Data was then pooled to compare between professions.

Patient and public involvement statement

The Prostate Cancer UK 'Policy & Campaigns Forum', consisting of men living with and after prostate cancer, initially raised the issues around ED after prostate cancer treatment as a suggested area of work for Prostate Cancer UK to focus on. The Forum members were subsequently involved in the planning of the study, including development of the research questions and survey design.

RESULTS

Survey of men with ED after prostate cancer treatment

Respondent characteristics

Complete responses from 561 men with ED after prostate cancer were received (a self-selecting convenience sample). Responses from 15 men who had not received treatment in the UK were excluded, leaving a total of 546 respondents for analysis (**Table 1**). The number of responses per question ranged from 408 to 546 (75-100% response rate) due to respondents selecting they did not know the answer or that the question did not apply to them.

The mean respondent age was 65 years, with half (n=280/546; 51%) of the study sample aged between 60-69 years (**Table 1**). Approximately half (n=286/546; 52%) of respondents had received their initial treatment for prostate cancer in the last 4 years. This sample closely resembles the prevalence dataset of all prostate cancer patients alive in England at the end of 2015 which shows 50% living 0-5 years, 33% 5 – 10 years, 16% 10 – 15 years and 5% 15 – 21 years after diagnosis.[26] The majority (n=356/542; 66%) of respondents had received only one treatment for prostate cancer, while 30% (n=160) received two and 5% (n=26) three. The most common treatment was radical prostatectomy (n=310/546; 57%), either alone (n=258; 47%) or in combination with other treatment(s) (n=52; 10%). One-quarter of patients (n=137/546; 25%) received EBRT and one-third (n=182; 33%) received androgen deprivation therapy (ADT) (**Supplementary File 3**).

Table 1. Characteristics of survey respondents with erectile dysfunction after prostate cancer treatment (n=546)

Country	
England	400 (73%)
Scotland	106 (19%)
Wales	37 (7%)
Northern Ireland	3 (1%)
Total	**546 (100%)**
Age (y)	
<50	9 (2%)
50-59	118 (22%)
60-69	280 (51%)
70-79	120 (22%)
≥80	19 (3%)
Total	**546 (100%)**
Sexual orientation	
Heterosexual	513 (94%)
Gay	17 (3%)
Bisexual	13 (2%)
Total	**543 (100%)**
Relationship status	
Married/civil partnership	422 (78%)
Have a partner, but not living together	34 (6%)
Do not currently have a partner	36 (7%)
Living with partner but not married/in civil partnership	31 (6%)
Widowed	21 (4%)
Total	**544 (100%)**
Years since first treatment for prostate cancer	
20 and above	3 (1%)
15 – 19	21 (4%)
10 – 14	55 (10%)
5 – 9	181 (33%)
0 – 4	286 (52%)
Total	**546 (100%)**
Number of prostate cancer treatments received	
1	356 (66%)
2	160 (30%)
3	26 (5%)
Total	**542 (100%)**

Percentages have been rounded to whole numbers.

Men's experiences prior to prostate cancer treatment

Almost three-quarters of respondents (n=401/546; 73%) indicated that they had 'always'/'almost always' been able to get and keep an erection before their prostate cancer treatment with only 2% (n=10) stating they were not sexually active before treatment (**Table 2**).

Over one-third (n=191/525; 36%) reported that their consultant was the first HCP to question them about their EF before treatment, while another third (n=182; 35%) reported that no one had asked about this (**Table 2**). Less than 10% (n=48/546; 9%) of respondents had completed a pre-treatment standard questionnaire, such as the Sexual Health Inventory for Men (SHIM) [27] or International Index of Erectile Function (IIEF) [28]. Men who were to undergo prostatectomy were more likely to be asked to complete a questionnaire, compared to men who were to receive radiotherapy with ADT (14% versus 6%, respectively).

Most respondents (n=447/546; 82%) were told by their doctor or nurse that ED might be a side effect of their treatment, however 12% (n=68) were not told this information. This information was more likely to be given to men before a prostatectomy, compared to radiotherapy and ADT (91% versus 74%, respectively) (**Table 2**). For respondents with a partner (n=473), 70% (n=332) said their partners were involved in these discussions with their HCPs. The knowledge

of possibly experiencing erection difficulties influenced the choice of prostate cancer treatment for 13% (n=74/546) of men.

Table 2. Men's experiences prior to prostate cancer treatment

How often were you [the patient] able to get and keep an erection before prostate cancer treatment? (n=546)				
	Total	**Surgery**	**RT+ADT**	**Other**
Almost always/always	**401 (73%)**	205 (79%)	75 (64%)	121 (71%)
Most times (>50%)	**64 (12%)**	21 (8%)	18 (15%)	25 (15%)
Sometimes (<50%)	**54 (10%)**	26 (10%)	13 (11%)	15 (9%)
Almost never/never	**14 (3%)**	4 (2%)	7 (6%)	3 (2%)
No sexual activity	**10 (2%)**	1 (0%)	3 (3%)	6 (4%)
Unsure	**3 (1%)**	1 (0%)	2 (2%)	0 (0%)
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**
Who asked the first questions about your [the patient's] erections before treatment? (n=525)				
	Total	**Surgery**	**RT+ADT**	**Other**
Your consultant	**191 (36%)**	123 (49%)	22 (20%)	46 (28%)
Your GP	**14 (3%)**	6 (2%)	2 (2%)	6 (4%)
Your Nurse	**35 (7%)**	17 (7%)	9 (8%)	9 (5%)
Your Partner	**4 (1%)**	1 (0%)	0 (0%)	3 (2%)
You [the patient]	**99 (19%)**	47 (19%)	19 (17%)	33 (20%)
No one	**182 (35%)**	55 (22%)	60 (54%)	67 (41%)
Total (% of total)	**525 (100%)**	**249 (47%)**	**112 (21%)**	**164 (31%)**
Did your [the patient's] doctor or nurse tell you [the patient] that erectile dysfunction might be a side effect of treatment? (n=546)				
	Total	**Surgery**	**RT+ADT**	**Other**
Yes	**447 (82%)**	235 (91%)	87 (74%)	125 (74%)
No	**68 (12%)**	11 (4%)	21 (18%)	36 (21%)
Unsure	**28 (5%)**	10 (4%)	9 (8%)	9 (5%)
ED not a side effect of the treatment I had	**3 (1%)**	2 (1%)	1 (1%)	0 (0%)
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**

Percentages in brackets are a percentage of each column, unless otherwise stated.

"Total" All men who took part in the survey and reported ED following treatment

"Surgery" Men whose only radical treatment was radical prostatectomy

"RT+ADT" Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT

"Other" All men who received a treatment other than "surgery" or "RT + ADT"

Men's experiences after prostate cancer treatment

Following prostate cancer treatment, half (n=229/437; 52%) of men were asked about their EF by their HCP within 3 months (**Table 3**), most commonly by their consultant, and this rose to 69% (n=156) in the group that had a prostatectomy. However, 29% (n=127) of all respondents said they had not been asked by any HCP about EF following prostate cancer treatment (**Table 3**). Almost a quarter (n=123/489; 23%) of men were not satisfied with the way that HCPs addressed their EF concerns.

Treatment for ED

Two-fifths of men (n=199/503; 40%) said they were offered ED treatment within 3 months of their prostate cancer treatment, with a further 19% (n=94) being offered treatment within 4-6 months. A fifth of men (n=110; 22%) said they were not offered any treatment (**Table 3**). Treatment was most commonly offered by a consultant (n=230/516; 45%) and usually in a urology department (n=181/503; 36%), GP surgery (n=120; 24%) or ED clinic (n=89; 18%).

ED management options men received for ED are shown in **Supplementary File 4** (n=521) – most commonly men were offered 3 options (n=122/521; 29%). The most common treatments offered were sildenafil 25, 50 or 100mg (16%, 20%, 17%), VED (33%), tadalafil 5, 10 or 20mg (21%, 14%, 29%) and pelvic floor exercises (20%), mostly on NHS prescription. The most common treatments prescribed privately were also PDE5is and VED.

When asked whether they had any difficulty or delays in getting access to ED treatment, one-quarter (n=103/431; 25%) indicated experiencing such problems. These included issues with supply and availability such as 'restricted availability due to limited prescriptions', 'pharmacies lacking stock', 'cost' and 'HCPs not being helpful/willing to prescribe/lacking knowledge'.

Table 3. Men's experiences after prostate cancer treatment

How soon after prostate cancer treatment, if at all, did the consultant, GP or nurse ask whether your ability to get or keep an erection had been affected? (n=437)				
	Total	**Surgery**	**RT+ADT**	**Other**
≤3 months	**229 (52%)**	156 (69%)	29 (33%)	44 (35%)
4-6 months	**59 (14%)**	34 (15%)	7 (8%)	18 (14%)
7-12 months	**16 (4%)**	5 (2%)	4 (5%)	7 (6%)
>12 months	**6 (1%)**	1 (<1%)	1 (1%)	4 (3%)
Not at all	**127 (29%)**	29 (13%)	46 (53%)	52 (42%)
Total (% of total)	**437 (100%)**	**225 (51%)**	**87 (20%)**	**125 (29%)**
How long after prostate cancer treatment, if at all, were you offered treatment to help you get or keep an erection? (n=503)				
	Total	**Surgery**	**RT+ADT**	**Other**
<3 months	**199 (40%)**	128 (54%)	24 (23%)	47 (29%)
4-6 months	**94 (19%)**	53 (22%)	12 (11%)	29 (18%)
7-12 months	**38 (8%)**	20 (8%)	6 (6%)	12 (8%)
>12 months	**28 (6%)**	8 (3%)	12 (11%)	8 (5%)
Unsure	**34 (7%)**	10 (4%)	9 (8%)	15 (9%)
Not at all	**110 (22%)**	18 (8%)	43 (41%)	49 (30%)
Total (% of total)	**503 (100%)**	**237 (47%)**	**106 (21%)**	**160 (32%)**

Percentages in brackets are a percentage of each column, unless otherwise stated.

"Total" All men who took part in the survey and reported ED following treatment

"Surgery" Men whose only radical treatment was radical prostatectomy

"RT+ADT" Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT

"Other" All men who received a treatment other than "surgery" or "RT + ADT"

Monitoring of ED treatment

Over three quarters of respondents (n=374/484; 77%) said they were not asked to complete a questionnaire about their erections, such as the SHIM or IIEF, during ED treatment. When asked whether their prescribed ED treatment met their needs, only 32% (n=128/402) said 'yes', while 51% (n=204) said 'no' and 17% (n=70) were 'unsure'. Approximately half

of the respondents (n=298/546; 55%) reported having access to a CNS, with the remainder saying they did not have access, or were uncertain.

Survey of primary and secondary healthcare professionals

Respondent characteristics

Complete responses from 282 HCPs were received. 21 responses were excluded from the analysis due to duplicate entries, leaving a total of 261 HCPs in the analysis (115 GPs, 52 practice nurses (four of whom were nurse practitioners/advanced nurse practitioners), 50 urologists and 44 urology CNSs) (**Table 4**).

Table 4. Characteristics of primary and secondary HCP survey respondents (n=261)

	GPs	Practice nurses	Urologists	Urology CNSs
Country				
England	97 (84%)	45 (91%)	41 (82%)	38 (86%)
Scotland	10 (9%)	0 (0%)	4 (8%)	2 (5%)
Wales	5 (4%)	4 (6%)	4 (8%)	3 (7%)
Northern Ireland	3 (3%)	3 (3%)	1 (2%)	1 (2%)
Total	**115 (100%)**	**52 (100%)**	**50 (100%)**	**44 (100%)**
Gender				
Male	64 (62%)	Not asked	40 (80%)	Not asked
Female	39 (38%)		10 (20%)	
Total	**103 (100%)**		**50 (100%)**	
Age (y)				
Under 30	1 (1%)	Not asked	3 (6%)	Not asked
30 - 39	42 (41%)		19 (38%)	
40 - 49	35 (35%)		20 (40%)	
50 - 59	21 (20%)		8 (16%)	
60 or over	4 (4%)		0 (0%)	
Total	**103 (100%)**		**50 (100%)**	
Average number of prostate cancer patients seen per month				
0 - 9	85 (74%)	46 (90%)	3 (6%)	Not asked
10 – 19	11 (10%)	0	16 (32%)	
20 - 29	8 (7%)	0	10 (20%)	
30 – 39	10 (9%)	5 (10%)	10 (20%)	
40 – 49	0 (0%)	0	3 (6%)	
50 – 59	0 (0%)	0	2 (4%)	
60 – 69	0 (0%)	0	2 (4%)	
70 – 79	0 (0%)	0	0 (0%)	
80 – 89	1 (1%)	0	2 (4%)	
90 – 100	0 (0%)	0	2 (4%)	
Total	**115 (100%)**	**51 (100%)**	**50 (100%)**	

Percentages have been rounded to whole numbers.

Knowledge and confidence in ED management within primary care

GPs and practice nurses were asked how confident they were that their knowledge of prostate cancer, ED and treatment options for ED was sufficiently comprehensive and up-to-date to support men with prostate cancer. Most GPs indicated their knowledge as 'satisfactory'/'confident'/'very confident' for prostate cancer (n=98/115; 85%), for ED (n=104; 90%) and for treatment options for ED (n=108; 94%), compared to 48% (n=25/52), 34% (n=18) and 32% (n=17) of practice nurses, respectively, with the remainder stating they were 'apprehensive' or 'extremely unconfident' (**Figure 1**). When asked what would help to improve their confidence, the most common responses were 'training/education' and 'further information/literature/online resources'.

Discussions about ED

Only 26% of GPs (n=30/115) and 32% of practice nurses (n=16/51) said they 'usually'/'always' initiated a discussion about ED with men after prostate cancer treatment, with 29% (n=33) and 38% (n=19) saying they 'rarely' or 'never' did so, respectively. This varied by gender for GPs, with 20% of male GPs (n=13/64) saying they 'never'/'rarely' initiated a discussion, compared with 44% of female GPs (n=17/39). The most common reasons GPs gave for not initiating a discussion about ED were that it 'wasn't a priority topic' or that 'the patient initiated the discussion'. However, 32% of GPs (n=37/115) said that men 'rarely'/'never' initiated a discussion about ED with them, while 25% of practice nurses (n=13/51) said the same. For GPs, this question varied less by gender than the previous question, with 33% of male GPs (n=21/64) saying patients 'never'/'rarely' initiated a discussion with them, compared with 41% of female GPs (n=16/39).

When secondary care HCPs were asked who was the most likely to initiate a discussion about ED, the majority of urologists (n=33/50; 61%) identified themselves, while for non-ED specialist CNSs (n=34) the most common first choice was the patient (n=12; 35%), followed closely by the urologist or urology/uro-oncology CNS (both n=11; 32%). A fifth of urologists (n=10/50; 20%) said that the duration of ADT would affect their decision whether to discuss ED with the patient, with the conversation more likely to take place for men on long-term ADT.

Involvement of partners in discussions about ED appeared to be more common in secondary care. 40% of urologists (n=20/50) versus only 13% of GPs (n=15/115) said they 'usually'/'always' involved men's partners in such discussions, while 24% of urologists (n=12/50) versus 60% of GPs (n=70/115) said they 'rarely'/'never' did so. Among the nurses surveyed, 65% of CNSs (n=28/43) said they involved partners, compared to only 12% of practice nurses (n=6/51).

Assessment of erectile function in secondary care

The majority of CNSs (34/44; 77%) and urologists (40/50; 80%) said they 'usually'/'always' performed a verbal baseline assessment of EF before treatment, with only 8% of urologists (n=4) saying they 'never'/'rarely' did this. Standardised questionnaires were used less frequently than verbal assessments by both urologists and CNSs. 30% (n=15/50) of urologists indicated that there were some patient groups they chose not to assess for baseline EF, for example if they were very elderly, had advanced disease or did not wish to be assessed. Other factors such as lifestyle, medication, comorbidities and relationships were also often included in the EF assessment.

Roles and responsibilities

Primary and secondary care HCPs were asked which HCPs or services they perceived as being involved in initiating, monitoring and following up on treatment for ED. The pattern of responses differed considerably between different HCP types, as shown in **Figure 2**. GPs and urologists had the most prominent role according to GPs and practice nurses, whereas urologists and CNSs identified themselves and dedicated ED services as playing the major roles. CNSs identified themselves as having a greater focus on monitoring and follow-up, rather than on management initiation.

Management of ED

In primary care, 39% of GPs (n=44/115) said that they 'usually'/'always' prescribed pharmacological management for men with ED after prostate cancer treatment, while 51% (n=59) said 'sometimes', and 11% (n=12) 'rarely'/'never' did. Only 23% of practice nurses (n=12/52) said that they offered ED management.

A large majority of GPs (n=104/111; 94%) and urologists (42/50; 84%) used oral therapy (PDE5is) as their first line treatment for ED in prostate cancer patients. The PDE5i most commonly prescribed by GPs was sildenafil (93%), whereas urologists most commonly prescribed tadalafil (96%). Most GPs prescribed a dose of 4 tablets per month: only 38% of GPs, compared to 69% of urologists, prescribed daily low dose (5mg) tadalafil (the only daily PDE5i licensed for daily use).

GPs were much less likely than urologists to use second- or third-line treatments, including VED (15% vs 86%), intracorporeal injections (35% vs 86%), intraurethral PGE-1/alprostadil (17% vs 58%), penile implants (9% vs 28%),

combination therapy (1% vs 50%), psychosexual therapy (12% vs 24%) and pelvic floor exercises (12% vs 20%) (**Figure 3**). A common reason for this would be that GPs would refer the patient to secondary or specialist care for these treatments. However, 41% of GPs (n=47/115) said they 'rarely'/ 'never' refer men with ED after prostate cancer treatment to secondary or specialist care.

Access to treatments

Treatments reported to be inaccessible to some GPs included penile implants (n=74/115; 64%), intracavernosal injections (n=51; 44%) and VEDs (n=48; 42%). Common reasons given were that these treatments were 'restricted to secondary care', 'not prescribed on the NHS' or there was 'a lack of training or expertise in their use'. Treatment access was less of an issue among secondary care HCPs: 56% of urologists (n=28) said that all ED treatments, including psychosexual therapy, were available to their patients.

DISCUSSION

Our survey of men explored the experiences of ED management after being treated for prostate cancer. In parallel surveys, we examined the knowledge and experience of primary and secondary HCPs in assessing such patients and their management strategies. Our findings indicated that, despite being at high risk from treatment-induced ED, many men were not treated according to recognised/available ED treatment guidelines available at the time of this study [20,29] and many were dissatisfied with their ED management. There was also an apparent mismatch between patient and HCP views on how post-treatment ED is managed in practice. It seems likely that, to some extent, HCPs' responses may have reflected their 'ideal' management rather than what actually took place in practice.

Management of ED in primary care

In particular, there seemed to be inadequate management of ED in primary care, including failure to implement early and structured strategies, combination ED management strategies and, in some instances, any ED treatment at all. These issues seemed to reflect restricted access to treatments and services and lack of confidence in managing ED. This suggests a need for better targeted training and education, particularly for practice nurses. Many GPs see relatively few prostate cancer patients, whereas practice nurses encounter men with ED more frequently, presumably when administering ADT injections or providing care for concomitant conditions, such as diabetes. In the UK there has been minimal under/postgraduate education in sexual medicine and human sexuality.[30,31] We also found a lack of assessment of EF before and after prostate cancer treatment, with low usage of formal/validated measurement instruments (e.g. IIEF, SHIM etc.) and no routine structured evaluation of ED management efficacy.

Communication between HCPs and patients

Communication between HCPs and patients was limited, with failures to initiate discussions about ED and/or involve partners in discussions. It was particularly worrying that 12% of men said they were not told that ED was a risk of prostate cancer treatment. Communication barriers between patients and HCPs are known to be a key factor in the under-reporting, and consequent under-treatment, of ED.[21,22] Understandably, HCPs may be hesitant to enquire into the personal aspects of men's lives which may explain why, in this study, female GPs were less likely to initiate a conversation about ED after prostate cancer treatment than male GPs. In addition, patients themselves may be too embarrassed to raise the issue,[32,33] believe that ED is an inevitable result of ageing and/or not know which HCP to ask for help.[22] Factors such as advanced patient age may deter GPs from enquiring about sexual activity.[34,35]

Although the men in our survey were not young (average age 65 years, with 25% aged ≥70 years), it was clear from their survey responses that sexual activity was still important to them. Other reports suggest that many men wish to continue sexual activity into their 8th and 9th decades.[36,37] Data from the diabetes setting has found patient embarrassment to be the most common reason for under-reporting of ED.[32] In male patients aged >30 years attending their physician, a brief patient questionnaire on EF was found to be an excellent aid for patients and physicians to prompt discussion about ED.[21] Patient reactions to the questionnaire included relief that the issue had been broached and the knowledge that help was available for ED. The Cancer Care Review (CCR), carried out by the GP or Practice Nurse within six months of the practice being notified an individual has a cancer diagnosis, is a component of the Recovery Package.[38] The CCR is a useful opportunity to discuss side effects of treatment, as part of a wider discussion. Despite the availability of CCR templates and guidance, CCRs are not always conducted in a systematic and consistent manner leading to variability in patient care and experience.[39]

As disease surveillance after treatment for prostate cancer generally occurs from 6 weeks post-treatment at 3-monthly intervals for at least 12 months in the UK,[10] it was disappointing that there were delays in initiating ED management within secondary care and poor communication within primary care. The necessary focus on disease surveillance in oncology clinics may result in low prioritisation of sexual difficulties. An observational study found that patients with prostate cancer were more likely to initiate a discussion about sexual function in the urology clinic than in the clinical oncology clinic (22% vs 4%), but nevertheless sexual concerns were not discussed at all in almost 50% of visits.[40]

Differences between HCP opinions

Importantly, we found considerable differences between HCP opinions regarding lead roles in the initiation, monitoring and follow-up of ED management: such confusion could easily lead to inadequate management and contradictory advice, as was evident from the men's survey results. These findings may reflect financial considerations and, in the case of nurses, whether or not they have a prescribing role. The increased role of primary care in the follow-up of

prostate cancer patients [41] requires unified management guidelines and support from Clinical Commissioning Groups regarding GP prescribing of relevant treatments with local guidelines and shared care protocols. While urologists and specialist ED clinics were most commonly identified as being responsible for prescribing ED treatment, this management route inevitably leads to delays, due to the need for specialist referral and limited access to specialist ED clinics.

Specific consensus guidelines for treating ED after prostate surgery [13] and radiotherapy/ADT [14] have been developed. These guidelines emphasise the importance of proactive early ED management, including patient education and pharmacological intervention, to minimise treatment-induced penile changes and the impact that loss of sexual desire and delayed ED may have on men and their partners.[13,14,42–44] The guidelines recommend daily and/or on-demand PDE5is as first-line treatment for patients who have undergone nerve-sparing prostatectomy.[13] PDE5is should be offered early after surgery, within the first month.[44,45] VEDs, alone or in combination with other modalities, may be used if other treatments have proved ineffective.

Access to treatments and specialist services

The finding in this study that many GPs did not prescribe treatments for ED is a matter for concern. Surprisingly, 44% of urologists did not have access to all ED treatments, despite NICE guidance.[10] NHS prescribing of PDE5is is often limited to once-weekly use, which may not adequately support men's needs or specialist sexual rehabilitation programme aims.[46] 'Stinting' on effective treatments such as PDE5is can be a false economy, potentially resulting in treatment failure and the need for expensive secondary referrals.[23,24] It is hoped that the recent availability of reduced cost generic sildenafil and tadalafil, and the lifting of restrictions on its daily use, will allow more men with ED to receive early treatment.

Lack of access to specialist ED services is known to be a challenge for effective ED management, with support from nurses being identified as a significant factor impacting patient outcomes. Sexual counselling is known to contribute to better efficacy, patient acceptance of, and compliance with other prescribed treatments for ED,[13] but was rarely offered in our survey. The National Prostate Cancer Audit (NPCA) 2014 annual report included results of an organisational audit of prostate cancer services in England and Wales. The audit showed 'sexual function services' to be available in 90% of NHS trusts in England and hospitals in Wales.[47] However, at the time, these data were inconsistent with findings from Freedom of Information requests submitted by Prostate Cancer UK in 2015 to 235 NHS health authorities across the UK to determine the availability of services (ED clinics, psychosexual clinics and counselling/sexual therapy) and treatments (daily low-dose tadalafil, VEDs and penile implant surgery) for men with ED after prostate cancer treatment. These results indicated poor availability of ED clinics, with only 51% of areas stating they offered this service, with wide geographical variation.[48] The NPCA repeated their organisational audit in 2016/17 and 2018/19 and reported that 'sexual function services' were available in 100% of NHS trusts in England and Health Boards in Wales, either provided on site or by the specialist MDT site.[49,50] Despite the published availability of support services, this does not necessarily translate through to men being offered intervention(s), accepting these interventions(s) or that these intervention(s) are helpful. Although not yet proven to be effective, novel support approaches have been developed in a bid to tackle this problem such as the Movember Foundation's TrueNTH initiative online self-management programme which provides personalised self-management strategies to help improve sexual wellbeing after prostate cancer.[51]

Limitations of the study

Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received. Men and HCP surveys were conducted separately and some response options differed between surveys, limiting direct comparisons. While HCPs generally answered all questions, many of the men's' survey questions were not answered and there were many 'unsure'/'don't know' or 'not applicable' responses. Men received a wide range of prostate cancer treatments - approximately half had undergone surgery (57%) - but we were unable to determine how many had undergone nerve-sparing prostatectomy, since this question was not asked. Compliance with ED treatment was not explored and data on ethnicity was not collected. We did not conduct a separate analysis of data from gay and bisexual men, due to the small sample size, although recent data suggest that this group may have additional support needs than do heterosexual men.[52] For the survey of men with prostate cancer, a "convenience sample" was collected, which may limit generalisability of our results. The split by time since diagnosis was representative of all men living with and after prostate cancer in England as of 2015 however, the men in this study were younger than the prostate cancer population as a whole – with 25% aged 70 and over in this study, compared with 75% in the prostate cancer population.[26] This is most likely explained by the use of online resources to recruit men into the study. As already noted, the surveys were conducted before the availability of generic and over-the-counter sildenafil and generic tadalafil.

CONCLUSIONS

In conclusion, our survey of men experiencing ED after prostate cancer treatment has confirmed findings in other published reports indicating that men living after prostate cancer treatment need better support from HCPs and more tailored and timely access to effective ED management. Results highlighted a lack of consensus over roles and responsibilities among HCPs: there needs to be a clearly defined pathway for discussion and management of ED, starting from the planning stage of prostate cancer treatment.

There is an urgent need for better education regarding ED management to be offered to primary care, particularly regarding the importance of early sexual rehabilitation, and for more high-quality evidence to support the recovery of sexual function following prostate cancer treatment.

FOOTNOTES

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Author contributions

AH and AD designed and administered the surveys, analysed the data and drafted the manuscript. IW and MK contributed to the study design, data interpretation and drafting of the manuscript. All authors edited the manuscript and gave final approval of the version to be published.

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Competing interests

None declared.

Data sharing statement

Due to the personal and sensitive nature of the survey data collected in this study, including substantial free-text answers, it is not ethically possible to make available the full dataset as this would compromise participants' anonymity and privacy.

Ethical approval statement

This study did not require an application for ethical approval, in line with the NHS Research Ethics Committee decision tool (http://www.hra-decisiontools.org.uk/ethics/). The study was assessed and approved by Prostate Cancer UK's Policy & Campaigns Forum, consisting of men living with and after prostate cancer, and Leadership Team. By completing the survey, respondents were consenting to be part of the study and were informed that their responses would be confidential and not used for any other purposes beyond this research study.

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FIGURE LEGENDS

Figure 1. Level of confidence among (a-c) GPs and (d-f) practice nurses that their knowledge of prostate cancer, ED and treatment options for ED is sufficiently comprehensive/up-to-date to support men with prostate cancer.

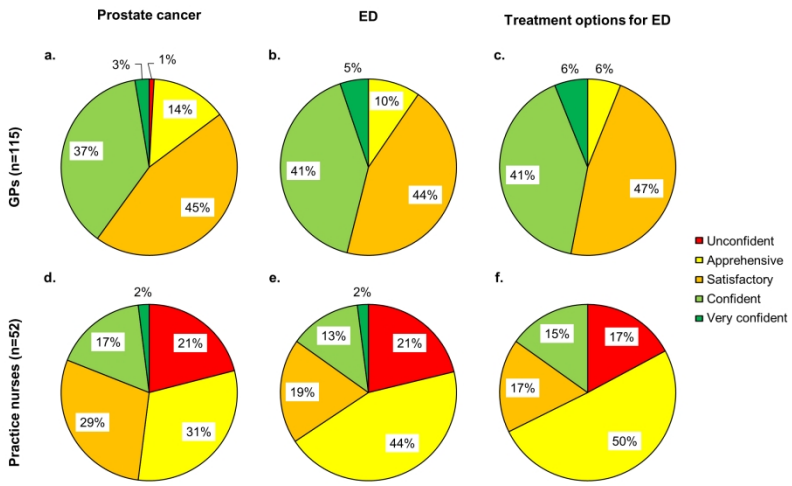
GPs were asked two separate questions about comprehensive knowledge and up-to-date knowledge. The data shown is for comprehensive knowledge. Practice nurses were asked a single question about comprehensive/up-to-date knowledge.

Figure 2. Roles and responsibilities of HCPs for the initiation, monitoring and follow-up of an ED management strategy according to (a) GPs, (b) practice nurses, (c) urologists and (d) CNSs.

HCPs could select more than one option from initiate (black), monitor (grey) or follow-up (white).

Figure 3. ED management strategies used after prostate cancer treatment by GPs (n=115) and urologists (n=50).

HCPs could select more than one option.



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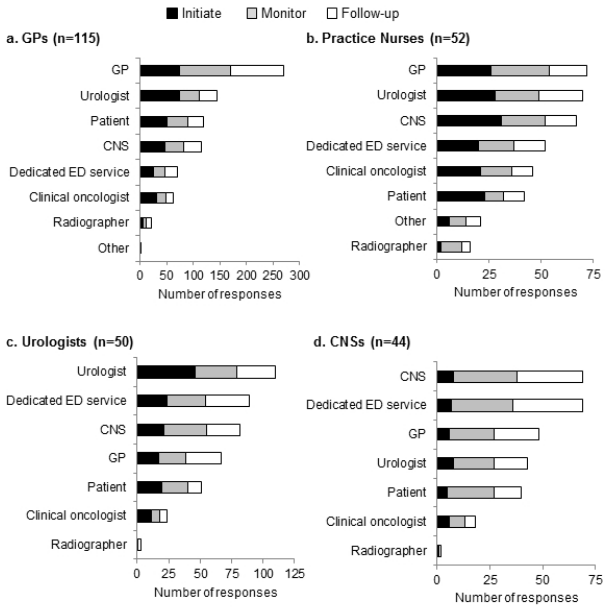

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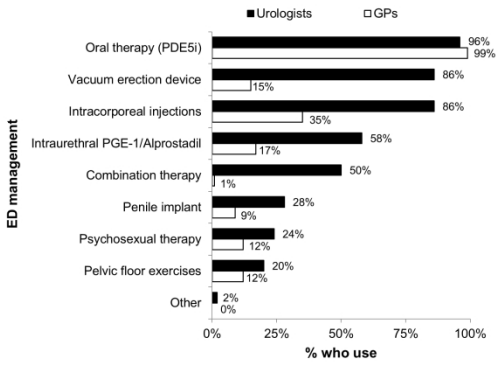

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HCPs could select more than one option.

254x190mm (300 x 300 DPI)

Supplementary File 1. Survey questions

Men with prostate cancer survey

Q1. Please tick the statement that best describes you:

I'm a man who's been treated for prostate cancer, and I have had trouble getting or keeping an erection after treatment *(the dataset used for analysis)*

I'm a man who's been treated for prostate cancer, but I have not had trouble getting or keeping an erection after treatment

Q2. How old are you?

Q3. When were you first treated for prostate cancer (year)?

Q4. When were you last treated for prostate cancer (year)? (please say if treatment is ongoing)

Q5. What is your relationship status?

Don't currently have a partner

Have a partner, but not living together

Living with a partner but not married or in a civil partnership

Married or in a civil partnership

Widowed

Q6. Do you consider yourself to be:

Heterosexual or straight

Gay

Bisexual

Q7. What type of prostate cancer treatment have you had (please select all that apply)?

Active surveillance

Watchful waiting

Surgery: open radical prostatectomy

Surgery: keyhole (laparoscopic) prostatectomy by hand

Surgery: keyhole (laparoscopic) prostatectomy using a robot

External beam radiotherapy

Permanent seed brachytherapy

Hormone therapy

Temporary brachytherapy

High intensity focused ultrasound (HIFU)

Cryotherapy

Chemotherapy

Unsure

Q8. Which hospital are / were you being treated in?

Q9. Where do you live (town or county)?

Q10a. Do, or did, you have access to a clinical nurse specialist (CNS)?

Yes

No

Unsure

***Q10b**. If yes, we would like to ask the CNS to complete a questionnaire about erectile dysfunction services.*

If you're willing to give us their contact details, please do so below:

Before prostate cancer treatment

Q11. Did the doctor or nurse ask about your erections before prostate cancer treatment?

Yes / No / Unsure

Q12. How often were you able to get and keep an erection before prostate cancer treatment?

Almost always or always

Most times (more than half the time)

Sometimes (about half the time)

A few times (less than half the time)

Almost never or never

No sexual activity

Unsure

Q13. Did you complete a questionnaire before prostate cancer treatment, for example the Sexual Health Inventory for Men (SHIM) or International Index of Erectile Function (IIEF) questionnaires?

Yes / No / Unsure

Q14. Did the doctor or nurse tell you that erectile dysfunction might be a side effect of treatment?

Yes / No / Unsure / Erectile dysfunction is not a side effect of the treatment I had

Q15. Did the possibility that you might experience erection difficulties influence the choice of prostate cancer treatment?

Yes / No / Unsure

Q16. Who asked the first questions about your erections before treatment?

The consultant

The GP

The nurse

Me

My partner

No one

Unsure

Other:

Q17. If you have a partner, were they involved in these discussions with your health professionals?

Yes / No / Unsure / Not applicable

Q18. If you have a partner, did you want them to be involved in these discussions?

Yes / No / Unsure / Not applicable

After prostate cancer treatment

Q19. After your prostate cancer treatment, which health professionals asked whether you had experienced any side effects?

The consultant

The GP

The nurse

No one asked

Unsure

Other:

Q20. How soon after prostate cancer treatment, if at all, did the consultant, GP or nurse ask whether your ability to get or keep an erection had been affected?

Q21. How soon after prostate cancer treatment, if at all, did you become concerned about your ability to get or keep an erection?

Q22. If you had concerns, were you satisfied with the way the health professional addressed your concerns about getting or keeping an erection?

Yes / No / Unsure / Not applicable

Q23. If you were not concerned about the ability to get or keep an erection immediately after treatment, did a health professional follow up on this question at a later date?

Yes / No / Unsure / Not applicable

Q24. If you did not experience erectile dysfunction immediately after treatment, did a health professional follow up on this question at a later date?

Yes / No / Unsure / Not applicable

Q25. If you have a partner, were they involved in these discussions with your health professionals?

Yes / No / Unsure / Not applicable

Q26. If you have a partner, did you want them to be involved in these discussions?

Yes / No / Unsure / Not applicable

Treatment for erection problems

Q27. How long after prostate cancer treatment, if at all, were you offered treatment to help get or keep an erection?

Q28. Who offered you treatment to help get or keep an erection?

The consultant

The GP

The nurse

No one offered treatment

Unsure

Other:

Q29. If you were given treatment to help get or keep an erection, were you asked if it was working, and if so, after how long?

Q30. If you have a partner, have you spoken to your partner about problems with your erections?

Yes / No / Unsure / Not applicable

Q31. Where are / were you being treated for problems with erections?

Urology department

Erectile dysfunction clinic

Psychosexual clinic

Counsellor/psychologist's office

Sex therapist's office

GP surgery

Didn't receive treatment

Unsure

Other:

Q32. Erection problems can be treated in a number of ways, and some treatments can be prescribed together. Which treatment(s) have you been offered on the NHS, or have you paid for privately, to help you get or keep an erection (please select all that apply)?

Viagra (sildenafil) tablets: 25 / 50 / 100mg

Cialis (tadalafil) tablets: 5 / 10 / 20mg

Levitra (vardenafil) tablets: 10 / 20mg

MUSE (Intra-urethral Alprostadil pellets): 125 / 250 / 500 / 1000ug

Caverject (Intra-cavernosal injections): 5 / 20 / 40mg

Viridal Duo (Intra-cavernosal injections): 10 / 20 / 40 mg

Vacuum erection device (penis pump)

Pelvic floor exercises

Sex therapy

Counselling

Don't know

None

Other (please describe)

Q33. For each of the treatments you've selected above, please tell us whether you combine(d) any of them (please give details):

Q34. For each of the treatments you've selected above, please tell us the number of times you tried them, and the length of time used (please also say if you are still using them):

Q35. What was your experience of each treatment or combination of treatments used? Was the treatment(s) helpful?

Q36. Have you had any difficulty or delays in getting access to the treatment(s)? (please explain)

Q37. Did the treatment(s) you were prescribed meet your needs?

Yes / No / Unsure / Not applicable

Q38. Did the doctor or nurse ask any questions about your erections, or ask you to complete a questionnaire while undergoing the treatments, for example the Sexual Health Inventory for Men (SHIM) or International Index of Erectile Function (IIEF) questionnaires?

Yes / No / Unsure / Not applicable

Q39. Have you been online to look for additional information and / or treatment? (if yes, please give details of the websites and any non-prescription treatment tried)

Q40. Are you still using any treatment to help get or keep an erection?

Yes / No / Unsure / Not applicable

Q41. How long have you been getting treatment for erection problems?

Q42. If you stopped treatment, please state why:

Q43. How have erection problems affected how you feel about yourself?

Q44. If applicable, what effect did, or do, your erection problems have on your relationship?

Q45. Is there anything that would have made your experience better? If so, what?

Q46. What is your opinion of the standard of care, information and support you have received from your GP, consultant and nurse?

Q47. Have you had any other sexual concerns or difficulties following treatment for prostate cancer? If so, please explain:

Q48. Have you sought help for any of these concerns or difficulties?

Yes, from the consultant

Yes, from the GP

Yes, from the nurse

Yes, from the counsellor

No

Unsure

Not applicable

Other:

Primary care survey (GPs and practice nurses)

S2 - Specialty confirmation
Are you a...
GP (1)
Practice Nurse (2)
Continence Adviser/Specialist (3)
Health visitor (4)
Other (5)
S2x Please specify 'Other'

S3 – Number of patients
In a three month period, on average how many patients will you see with a diagnosis of prostate cancer?
Please state the total number of patients, not individual consultations

D1 – Gender (GPs)
Are you...
Male (1)
Female (2)

D2 – Age (GPs)
Are you...
Under 30 (1)
30 - 39 (2)
40 - 49 (3)
50 - 59 (4)
60 or over (5)

D3 – Practice location (GPs)
Is your practice based in a...
Rural area (1)
Urban area (2)
Semi-rural area (3)
Suburban area (4)
Other (5)

D4 - Region
Whereabouts are you currently practising?
[Select from a list of UK regions and devolved nations]
Retired (14)
Not practising in the UK (15)

D5 – CCG
Which Clinical Commissioning Group do you primarily work in?
[Select from a list]
Other (212)

Q2 - Frequency
Thinking of the consultations for patients with prostate cancer, in an average month, how often would you expect to see any patient with prostate cancer?
All consultations, not individual patients.

Q3 - ED Discussion initiations
In relation to patients who have been diagnosed with/treated for prostate cancer, how often do you initiate a discussion about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q3b - Follow up for regular initiation of ED discussion
You indicated that you [show answer from above] initiate a discussion about ED, could you please explain when and how the conversation is initiated in the treatment pathway?

Q3c - Follow up for non- initiation of ED discussion

You indicated that you [show answer from above] initiate a discussion about ED, could you please explain why this conversation is [show answer from above] initiated?

Q4 - ED Patient initiations
How often do prostate cancer patients initiate a discussion with you about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q5 - ED Partner discussions
How often do you involve the partner of prostate cancer patients in discussions about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q6 - Wider treatment
In the treatment of prostate cancer more widely, who would you expect to initiate, monitor and follow-up an ED management strategy?
Please check all that apply.
Patient (1)
Urologist (2)
Clinical oncologist (3)
Urology/uro-oncology nurse specialist (4)
Dedicated ED service (5)
Radiographer (6)
GP (7)
Other (please state) (8)

Q7 - Point in pathway for ED discussion
At what point(s) in the patient pathway would you expect a discussion regarding ED to normally take place?
Please check all that apply.
Not routinely discussed (1)
At diagnosis of prostate cancer (2)
Prior to surgery (3)
Prior to radiotherapy (4)
Prior to initiation of ADT (5)
Any time during treatment (6)
After treatment/during follow up (7)
Other (please state) (8)
Don't know (9)

Q8 - Prostate cancer knowledge
Please indicate how confident you are in relation to the following statements regarding your knowledge of prostate cancer.
Extremely unconfident (1)
Apprehensive (2)
Satisfactory (3)
Confident (4)
Very confident (5)

I am confident that my knowledge of prostate cancer is sufficiently comprehensive to support men with prostate cancer (1)

I am confident that my knowledge of prostate cancer is sufficiently up to date to support men with prostate cancer (2)

Q8a - Follow up for 'comprehensive'
You indicated that you are [show answer from above] that your knowledge of prostate cancer is sufficiently comprehensive to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q8b - Follow up for 'up to date'
You indicated that you are [show answer from above] that your knowledge of prostate cancer is sufficiently up to date to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q9 - ED knowledge
Please indicate how confident you are in relation to the following statements regarding your knowledge of ED.
Extremely unconfident (1)
Apprehensive (2)
Satisfactory (3)
Confident (4)
Very confident (5)

I am confident that my knowledge of ED is sufficiently comprehensive to support men with prostate cancer (1)

I am confident that my knowledge of ED is sufficiently up to date to support men with prostate cancer (2)

Q9a - Follow up for 'comprehensive'
You indicated that you are [show answer from above] that your knowledge of ED is sufficiently comprehensive to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q9b - Follow up for 'up to date'
You indicated that you are [show answer from above] that your

knowledge of ED is sufficiently up to date to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q10 - ED treatment options knowledge
Please indicate how confident you are in relation to the following statements regarding your knowledge of treatment options for ED.
Extremely unconfident (1)
Apprehensive (2)
Satisfactory (3)
Confident (4)
Very confident (5)

I am confident that my knowledge of the treatment options for ED is sufficiently comprehensive to support men with prostate cancer (1)

I am confident that my knowledge of the treatment options for ED is sufficiently up to date to support men with prostate cancer (2)

Q10a - Follow up for 'comprehensive'
You indicated that you are [show answer from above] that your knowledge of the treatment options for ED is sufficiently comprehensive to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q10b - Follow up for 'up to date'
You indicated that you are [show answer from above] that your knowledge of the treatment options for ED is sufficiently up to date to support men with prostate cancer. Please indicate how you believe this could be improved.
Please answer as fully as possible

Q11 - Manage ED
In relation to prostate cancer patients, do you prescribe treatment for ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q11a - Follow up
You indicated that you [show answer from above] prescribe treatment for ED. Please explain why that is.
Please answer as fully as possible

Q12 - ED treatments
Please indicate which of the following treatments are used by you or by other doctors in your practice for managing treatment of ED in prostate cancer patients.
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q13 – First-line treatment
Which of the treatments used by you or by other doctors in your practice is your/their first line choice for managing ED in prostate cancer patients?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q13a - Oral treatment details
You said that you or other doctors in your practice typically use oral therapy in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drug:
Dose:
Frequency:
Comments:

Q13b - Combination treatment details
You said that you or other doctors in your practice typically use combination therapies in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drugs:
Dose:
Frequency:
Comments:

Q14 - Options not available
Please indicate if any of the following treatments are not accessible at your practice.
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)
None of the above - all are available (10)

Q14a - Options not available reasons
You indicated that the following treatments are not accessible at your practice. Please explain why they are not available.
Please answer as fully as possible.

Q15 - Ideal first-line treatment
Assuming all treatment options were available to you, what would be your first line of treatment?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)
None of the above - all are available (10)

Q16 - Referral
Do you refer prostate cancer patients with ED on to secondary or specialist care?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q16a - Why not referred
You indicated that you never refer prostate cancer patients with ED on to secondary or specialist care. Please explain why that is.
Please answer as fully as possible

Q16b - To whom referred
You indicated that you refer prostate cancer patients with ED on to secondary or specialist care. Please indicate where these referrals are made.
Please select all that apply
ED specialist (1)
Sexual therapist (2)
Urologist (3)
Other (please state) (4)

Q16c – Most common referral
You indicated that you make referrals to the following specialists. Please select the specialist where you make the most referrals.
Please select one option
ED specialist (1)
Sexual therapist (2)
Urologist (3)
Other (please state) (4)

Secondary care survey (urologists and CNSs)

Please choose the option that is most applicable to you:

I specialise in erectile dysfunction (e.g. urologist specialising in ED, sexual advisor/therapist)

I specialise in urology (e.g. urologist not specialising in ED, urology nurse)

S2 – Specialty (urologists)
Which of the following best describes your specialty?
Please select one option
Urology (1)
Oncology (2)
Other (please specify) (3)

S3 – Number of patients (urologists)
In a three month period, on average how many patients will you see with a diagnosis of prostate cancer?
Please state the total number of patients, not individual consultations

S4 – Seniority (urologists)
Which of the following best describes your seniority?
Please select one option
Consultant (1)
Associate Specialist (2)
Staff Grade / Specialty Doctor (3)
Clinical Research Fellow (4)
Specialty Trainee / Registrar Years 5+ (5)
Specialty Trainee / Registrar Years 3-4 (6)
Specialty Trainee / Registrar Years 1-2 (7)
FD2 (8)
FD1 (9)
Other (please specify) (10)

D1 – Gender (urologists)
Are you...
Male (1)
Female (2)

D2 – Age (urologists)
Are you...
Under 30 (1)
30 - 39 (2)
40 - 49 (3)
50 - 59 (4)
60 or over (5)

D3 – Region (urologists)
Whereabouts are you currently practising?
[Select from a list of UK regions and devolved nations]
Retired (14)
Not practising in the UK (15)

D4 - Trust/health board (urologists)
In which trust do you primarily work?
[Select from a list]
Other (204)
Retired (234)

Q1 – Initiate discussion (urologists)
Thinking of the consultations for patients with prostate cancer, who would be most likely to initiate a discussion about ED?
Please select all that apply
Patient (1)
Urologist (2)
Clinical Oncologist (3)
Urology/uro-oncology nurse specialist (4)
Radiographer (5)
GP (6)
Other (please state) (7)

Q2 - Ranking Initiate discussion (urologists)
From the list below, please rank your choices in order of likelihood to initiate a discussion about ED.
Please enter 1 for most likely, 2 for second, 3 for third etc.
Patient (1)
Urologist (2)
Clinical Oncologist (3)
Urology/uro-oncology nurse specialist (4)
Radiographer (5)
GP (6)
Other (7)

Q2a - Initiate discussion follow up (urologists)
You indicated that the [show answer from above] was most likely to initiate a discussion about ED.
Can you please explain why the discussion is most likely to be initiated by the [show answer from above]?
Please answer as fully as possible

Q3 – Pathway (urologists)
Thinking about patients with prostate cancer, where in the patient pathway would you expect a discussion about ED to take place?
Please select all that apply
Not routinely discussed (1)
Prior to initiation of ADT (2)
Prior to radiotherapy (3)
Prior to surgery (4)
After treatment / during follow up (5)
Any time during treatment (6)
Other (please state) (7)

Q4 - ED Discussion initiations (urologists)
How often do you involve the partner of prostate cancer patients in discussions about ED?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Assessment

Q5 - EF Baseline
Do you perform any baseline assessment of erectile function (EF) before treatment for prostate cancer?
Please select one option per row, apart from the 'Other' row if you don't need to specify any other baseline assessment.
Never (1) / Rarely (2) / Sometimes (3) / Usually (4) / Always (5)
For:
Verbal assessment (1)
IIEF (2)
IIEF-5 (3)
EDITS (4)
Other (Please state) (5)

Q5a - EF Baseline follow up
Please provide any additional comments regarding the use of [show answer from above] in assessing baseline EF before treatment for prostate cancer.

Q6 - No EF Baseline
Are there any patient groups you choose NOT to baseline assess for EF?
Yes (1)
No (2)

Q6a - NO EF baseline groups
Please specify the patient groups you choose NOT to baseline assess for EF.
Please use a separate text box for each group.

Q6b - No EF Baseline rationale
You said that you choose NOT to baseline assess the groups below for EF. Could you please explain why that is?
Please answer as fully as possible

Q7 - ADT
Would the duration of intended androgen deprivation therapy (ADT) affect your decision to discuss ED?
Yes (1)
No (2)

Q7a - ADT follow up
You said that the duration of intended androgen deprivation therapy (ADT) would affect your decision to discuss ED. Could you please explain why this is?
Please answer as fully as possible

Q8 - Assessment of impact on EF
In the context of prostate cancer, do you make an assessment of the impact of any of the following factors upon EF?
Please select all that apply
General lifestyle (1)
Medication(s) (2)
Cardiac Disease status (3)
Metabolic status / Diabetes (4)

Co-morbidities (5)
Psychological factors (6)
Relationship factors (7)
Other (Please state) (8)
None of the above (9)

Q9 - Discussion of impact on EF
Of the factors that you assess the impact of upon EF in prostate cancer patients, how often do you discuss these with the patient?
Please select one option per row
For the answer options above:
Never (1) / Rarely (2) / Sometimes (3) / Usually (4) / Always (5)

Q10 - Testosterone measurement
How often do you measure testosterone levels in men with prostate cancer?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q10a - Testosterone follow up
You said that you [show answer from above] measure testosterone levels in men with prostate cancer. Could you please explain what circumstances prompt this measurement?
Please answer as fully as possible

Referral

Q11 – Referrals (ED specialists)
How is a patient typically referred to your service (by who, when etc)?

Q12 - ED services offered (non-ED specialists)
What type(s) of ED support services are available for your patients?
Please select all that are available
An ED clinic (1)
VCD (Vacuum Constriction Device) demonstrations (2)
Psychological support (3)
Other (Please state) (4)
No ED support services are available (5)

Q12a - ED Clinic details (non-ED specialists)
Please give details of the ED clinic available for your patients
Please answer as fully as possible
Staffing, e.g. nurse specialist:
Frequency, e.g. weekly:
Support available, e.g. Counselling, sexual therapist, VCD demonstrations:

Q12b - Referral to ED support (non-ED specialists)
What proportion of patients with prostate cancer do you refer to ED support?
Please enter a percent of patients referred to ED support

Q12c - Referral to ED support – comments (non-ED specialists)
Please provide any additional comments about referrals to ED support, in particular groups of patients to whom this is applicable, and referral pathways which you follow
Please answer as fully as possible
Patient groups: (1)
Referral pathways: (2)

Q12d - NO ED Support (*non-ED specialists*)
You said that you do not have any ED support service available for your patients, could you please explain why not?
Please answer as fully as possible

Management & treatment strategies

Q13 - Wider treatment
In the treatment of prostate cancer more widely, who would you expect to initiate, monitor and follow-up an ED management strategy?
Please check all that apply.
Patient (1)
Urologist (2)
Clinical oncologist (3)
Urology/uro-oncology nurse specialist (4)
Dedicated ED service (5)
Radiographer (6)
GP (7)
Other (please state) (8)

Q14 - Assessment of ED at follow up
For patients with prostate cancer, do you personally assess and discuss ED at follow-up appointments?
Never (1)
Rarely (2)
Sometimes (3)
Usually (4)
Always (5)

Q14a - Lead follow up ED discussion
You said that you [show answer from above] assess and discuss ED at follow-up appointments. Who would normally lead the discussion?
Please select all that apply
Yourself (1)
Urologist (2)
Specialist Nurse (3)
Patient (4)
Oncologist (5)
Other (Please state) (6)

Q15 - Treatment Options
For prostate cancer patients which of the following treatment options for ED do you typically use?
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q15a - Oral treatment details
You said that you typically use oral therapy in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drug:
Dose:
Frequency:
Comments:

Q15b - Combination treatment details
You said that you typically use combination therapies in managing ED. Please state which drugs are prescribed, with their dose and frequency.
Please answer as fully as possible.
Drugs:
Dose:
Frequency:
Comments:

Q16 – Preference of treatment available
Of the treatment options for ED typically in use, which is your personal preference?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Q17 - Options not available
Please indicate if any of the following treatments for ED are not accessible to your patients.
Please select all that apply
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)
Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)
None of the above - all are available (10)

Q18 - Ideal first-line treatment
Assuming all treatment options were available to you, what would be your first line of treatment for ED?
Please select one option
Oral therapy (PDE5 inhibitors) (1)
Intracorporeal injections (2)
Intraurethral PGE-1/Alprostadil (3)
Vacuum constriction device (VCD) (4)

Pelvic floor exercises (5)
Psychosexual therapy (6)
Penile implant (7)
Combination therapy (8)
Other (Please state) (9)

Supplementary File 2. STROBE Statement - checklist of items that should be included in reports of ***cross-sectional studies***

	Item No.	Recommendation	Page No.
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	4
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	4
Study size	10	Explain how the study size was arrived at	4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	4
		(*b*) Describe any methods used to examine subgroups and interactions	4
		(*c*) Explain how missing data were addressed	4

		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5, 9
		(b) Give reasons for non-participation at each stage	
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	5, 9
		(b) Indicate number of participants with missing data for each variable of interest	5 - 11
Outcome data	15*	Report numbers of outcome events or summary measures	5 - 11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	5 - 11
		(*b*) Report category boundaries when continuous variables were categorized	5 - 11
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	5 - 11
Discussion			
Key results	18	Summarise key results with reference to study objectives	11, 12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12, 13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11, 12, 13

Generalisability	21	Discuss the generalisability (external validity) of the study results	11, 12, 13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Supplementary File 3. Treatments received for prostate cancer (n=546)

	Total	Surgery	RT+ADT	Other
Active surveillance*	**30 (5%)**	15**	2**	13 (8%)
Watchful waiting*	**19 (3%)**	6**	4**	9 (5%)
Chemotherapy	**7 (1%)**	n/a	n/a	7 (4%)
Cryotherapy	**6 (1%)**	n/a	n/a	6 (4%)
EBRT	**137 (25%)**	n/a	91 (77%)	46 (27%)
HIFU	**4 (1%)**	n/a	0	4 (2%)
ADT	**182 (33%)**	n/a	118 (100%)	64 (38%)
Brachytherapy (all)	**40 (7%)**	n/a	11 (9%)	29 (17%)
Permanent seed	*27 (5%)*	*n/a*	*5 (4%)*	*22 (13%)*
Temporary	*13 (2%)*	*n/a*	*6 (5%)*	*7 (4%)*
Radical prostatectomy (all)	**310 (57%)**	258 (100%)	n/a	52 (31%)
Standard laparoscopic	*102 (19%)*	*92 (36%)*	*n/a*	*10 (6%)*
Robotic-assisted laparoscopic	*73 (13%)*	*69 (27%)*	*n/a*	*4 (2%)*
Open	*135 (25%)*	*97 (38%)*	*n/a*	*38 (22%)*
Total (% of total)	**546 (100%)**	**258 (47%)**	**118 (22%)**	**170 (31%)**

ADT = androgen deprivation therapy; EBRT = external beam radiotherapy; HIFU = high-intensity focused ultrasound; RT = radiotherapy (including brachytherapy)

Percentages in brackets are a percentage of each column, unless otherwise stated. Respondents could select more than one answer except if brachytherapy (all) or radical prostatectomy (all) was selected, then only one subtype could then be chosen.

"Total" All men with ED after prostate cancer treatment

"Surgery" Men whose only radical treatment was radical prostatectomy

"RT+ADT" Men who only had radiotherapy (EBRT and/or brachytherapy) plus ADT

"Other" All men who received a treatment other than “surgery” alone or “RT + ADT” alone

* Includes patients who started on active surveillance/watchful waiting who went on to receive radical treatment.

** Data excluded from the percentage calculations.

Supplementary File 4. Treatments received for ED (n=521)

	Number of responses	% of respondents
Viagra (sildenafil) 25mg	81	16%
Viagra (sildenafil) 50mg	105	20%
Viagra (sildenafil) 100mg	91	17%
Cialis (tadalafil) 5mg	110	21%
Cialis (tadalafil) 10mg	71	14%
Cialis (tadalafil) 20mg	152	29%
Levitra (vardenafil) 10mg	30	6%
Levitra (vardenafil) 20mg	53	10%
MUSE (i/u alprostadil) 125ug	23	4%
MUSE (i/u alprostadil) 250ug	31	6%
MUSE (i/u alprostadil) 500ug	21	4%
MUSE (i/u alprostadil) 1000ug	20	4%
Caverject 5mg	38	7%
Caverject 20mg	65	12%
Caverject 40mg	20	4%
Viridal Duo 10mg	7	1%
Viridal Duo 20mg	10	2%
Viridal Duo 40mg	9	2%
Vacuum erection device	170	33%
Pelvic floor exercises	104	20%
Sexual therapy	3	1%
Counselling	11	2%
Don't know	4	1%
None	108	21%

Respondents could select more than one answer.